IN FORMATION 1993

ISSUE No. 2 MARCH

THE NEWSLETTER OF THE IN GROUP

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

INFLAMMATORY NEUROPATHIES

by Dr BRUCE DAY,

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

In using the term "Inflammatory Neuropathies", we are introducing a source of confusion. Inflammation denotes the presence of the body's defensive cells at the site of pathology. This may occur in a variety of neuropathies and may indeed be inconspicuous in the acquired demyelinating neuropathies. The IN Group concerns itself mith patients mho have or have had variants of the so-called acquired demyelinating neuropathies.

We use the term "acquired" to distinguish these disorders from the inherited demyelinating neuropathies. The term "demyelinating" refers to the process whereby the myelin lining of the nerve is removed. Myelin is a thin sheet of insulating material wrapped around most individual nerve fibres and is primarily responsible for the rapid conduction of the "electrical information along the nerve. Even relatively small amounts of damage to myelin can severely impair nerve function and produce major disability.

The acquired, demyelinating neuropathies constitute a broad spectrum of diseases from rapidly progressing disorders producing medical emergencies to indolent disorders producing minor but intractable symptoms which defy all but the most sophisticated attempts at diagnosis. These conditions continue to surprise even the most experienced physicians in the great variety of ways they can manifest themselves.

At the acute end of the spectrum is the condition widely known as Guillain Barre syndrome (GBS). It is also referred to in the medical literature as Landry Guillain Barre Strohl syndrome or acute inflammatory demyelinating polyneuropathy (AIDP). This condition conspicuosly progresses (usually with increasing weakness) over several days to several weeks, then stabilizes and gradually recovers. It is the most likely of all these disorders to affect the muscles of respiration and the patient may require ventilatory support in an intensive care unit until recovery occurs. The likelihood of complete recovery is high although patients with more severe nerve damage may take months to years to fully recover and some are left with permanent disability. This disorder often follows a respiratory infection or less common;y gastroenteritis. Many unusual variants are described such as those that affect balance and eye movements (Miller Fischer variant), the cranial nerves (polyneuritis cranial) and the ability to maintain blood pressure (pure pandy-sautonomia). All these variants in pure form are rare.

The chronic inflammatory demyelinating polyneuropathy disorders (CIDP) are even more varied in their manifestations. Many of these patients develop gradual worsening limb weakness and impaired sensation. The respiratory muscles are rarely significantly affected. The condition may wax and wane over months or may recover for many years only to recur again. Some patients may have only one limb affected often defying diagnosis until it spreads to involve other limbs. Some patients appear to have a disorder which mimics motor neuron disease. Preceding infections are less common or maybe less commonly remembered given the passage of time.

Underlying illnesses are more common than in AIDP, many of which are serious conditions. These possible underlying disorders are carefully searched for by the managing doctor through a series of blood tests and sometimes more invasive investigations. The vast majority of patients however prove to have no associated condition.

Some patients appear to have **an** intermediate disorder between the acute and chronic variants and some patients may switch such that the first time they get the condition it appears to be the acute variant whereas subsequent attacks are more chronic or vice versa. Given that the phenomenology of these disorders is only beginning to be understood it is not surprising that little is known of the true incidence or the predisposing factors responsible for these conditions. *I* expect that these disorders are a good deal more common than is widely believed and that there are many patients with milder variants that never get a satisfactory diagnosis. There is certainly a great deal of phenemonological research yet to be done. It is not known for example if these conditions are more common amongst certain racial groups or at certain latitudes as is the case with multiple sclerosis. The first step, of course, in undertaking any such research is accurate case ascertainment (correct diagnosis so that the research sample does not include patients with different disorders or exclude patients with inflammatory demyelinating neuropathy.

Although the diagnosis is sometimes severe on clinical grounds alone, the most poerful diagnostic investigation for these disorders is electrodiagnost-ic testing of the peripheral nerves and muscles. These tests are also known as nerve conduction studies and electroray-ography. Although a little uncomfortable the tests are free of side effects and are frequently so characteristic as to make other tests such as nerve biopsy unnecessary. Other tests such as lumbar puncture to examine the protein level in the spinal fluid are frequently helpful in supporting the diagnosis. On rare occasions a nerve biopsy is required to confirm the diagnosis. Although the surgery required for nerve biopsy is minor, the preparation of the specimen requires great care and skill to yield accurate results and is therefore only done in selected institutions.

Once the diagnosis is secure and, in some cases, even when the physicians cannot be absolutely sure of the diagnosis, a variety of treatments are considered. Not all patients require treatment however. In some cases the patient is clearly improving spontaneously whereas in others the patient may have such minimal symptoms that they are happy to "wait and see". The majority do require some therapy and in these cases treatment is tailored to the type of demyelinating neuropathy and to the risk of potential side effects.

In AIDP or GBS, studies show that early treatment with plasma exchange and more recently Immunoglobulin therapy improve the outcome, usually in terms of shortening the amount of time in hospital. These treatments are largely free of side effects although plasma exchange can be hazardous to patients with unstable blood pressure from the neuropathy.

Usually if one type of treatment does not work then others are tried. It is not possible at this stage to predict accurately which treatment is best for any one patient so physicians tend to try the least hazardous therapies first and, if no clear benefit ensues, step up to the next therapy.

With chronic forms of the illness other medications are frequently tried, sometimes as the first option. Of these the best known are steroid medications. Steroids have not been shown to be useful in the acute illness and may even make the situation worse but in chronic disease they are often beneficial, sometimes strikingly so. Long term steroid treatment is not innocuous, carrying the risk of many side effects. These medications are therefore used with considerable reservation and the patient needs to be carefully followed by the physician.

In desperate situations even more powerful immunosupprsssant medications are used. These carry the risk of excessively lowering the white blood cell count and thus exposing the patient to risk of severe infection. Patients taking these medications need to be more frequently reviewed and their blood count assessed. They are warned to be

quickly assessed by a doctor if they should develop a fever or other sign of infection, sore throat, abnormal bruising or bleeding. Fortunately it is only on rare occasions that one is forced to use such medications.

There are many other aspects to the management of patients with these disorders. Advances in intensive care nursing skills and technology have greatly improved survival for these conditions.

For patients with persisting weakness despite adequate therapy, neurore-habilitation experts are frequently able to assist with foot splints and leg braces, devices to improve dexterity when feeding, writing, reading, etc. Occupational and physio therapists are often of great assistance in helping reorganise the home to improve mobility, remove hazards and to train the patient to safely use the bathroom, kitchen, stairs, etc. Their many skills may make the difference between managing at home and requiring a nursing home admission. Fortunately very few patients ever become so badly disabled with these disorders.

In summation we can say we still have a long way to go to fully understand and cure these conditions.

IN CONTACT NETWORK

The IN CONTACT Network is becoming established on a formal basis.

I have written to the Fairfield, Alfred and Box Hill Hospitals advising them that the Network has been established as a means of giving support to GBS and CIDP sufferers and also to provide continuing information to help determine the incidence and prevalence of these disorders.

Each of the Hospitals has been advised of its assigned IN CONTACT Person (Fairfield - James Gerrand, Alfred -Roy Potter, Box Hill - Graham Blanck) and asked to nominate an official who will advise our CONTACT Person of any new patient diagnosed as a GBS or CIDP sufferer.

I will be sending similar letters to the other Melbourne major hospitals Austin, Repatriation, Royal Melbourne, Royal Childrens, Western, Monash Medical Centre, St Vincents - as well as those country hospitals in the areas where we have already informally estab-lilftKS OMftCY Per-sofis flflangaratta -Vilma Clarke, Kerang/Wakool - Doss Mills, Western District - Greg Gilles-pie, Taralgon - Stuart Vincent).

I would welcome further offers of becoming an IN CONTACT Person, particularly for country areas not already covered.

As well as a means of providing support we can expect a steady flow of new members from the workings of the Network.

James Gerrand,
Director.

IN GROUP NEWS

Membership

Membership now stands at 74 including 47 present and past sufferers of GBS or CIDP with the other 27 being patrons, committee, family and friends.

Of the 120 past patients of Fair-field Hospital since 1985 we were able to contact some fifty of whom twenty-five have joined the Group. Donations Tax Deductible

The Australian Taxation Office has accepted The IN Group Inc as a public benefit institution, so gifts (donations) of $2 and upwards to the Group are an allowable income tax deduction. I will supply receipts to those who wish them.

This means also that goods we may purchase for Group use will be conditionally exempt from Sales Tax. Register for Inflammatory Neuropathy

The Register for Inflammatory Neuropathy in Victoria, established to help research into the GBS and CIDP disorders ^ *nau has* 44, ^{£^5 TlQWl £®3t Pltl-ents of Fairfield Hospital who have given their permission.

Further entries from 10 other willing patients are awaiting the inspection of their medical records. Those IN Group members who have yet to sign the agreement form are invited to do so. A form is enclosed in this newsletter for those concerned. Next Get-Together

We hope to see you at The IN Group Get-Together on Tuesday 11th May, 7.30pm at 4 Alandale Ave Balwyn.

Dr BRUCE DAY will discuss "Pain Management".

Details are in the leaflet enclosed.

CARE OF THE IN PATIENT

From the address by .KATE FIELDING, Sister-in-charge Ward 3A, Al Hospital, to the meet£&8 of The IN Group at 4 Alandale Ave Balwyn on 9/2 JHG.

The creation of The IN Support Croup has been most welcome. It is very difficult to explain to patients' families as well as to other staff what it =means to a person to suffer from inflami^ptory neuropathy. Providing information is the starting point to improving c^wdit-ions for all IN patients.

All patients present individual challenges for nursing, IN patie^[3] more so. The incidence is low so MOV ward staff never get the opportunity °rf looking after IN patients. Plan/ .with the disorder are looked after as outpatients through plasma exchange proa-rams, etc. Also^ not all hospitals K&.u^ neurology wards. This is particularly so in country areas. By the time a *$&*\'~ ient has been diagnosed and sent Jown to a larger referring hospital the staff have been working with t^« patient sometimes for several days and d.re. unaware of the problems.

There is such a variety in the way IN patients can present that it takes a number of years of working in the area to have seen any pattern and to understand their special needs.

Many of the nursing challenges arise from the dichotomy of an intact mind in a paralysed body. The spirit is affected even though we say it is a disease of physical disability. It is an emotionally and spiritually terrifying experience. This needs to be remember*[2]^ bv all staff.

Some of the doubts that patients have of ever being normal again and the rage and distress of being dependent are entirely related to the IN process and can't be separated out as a physical process. Some may say that is what the occupational or physio therapist was doing. It should be remembered that these and speech therapists evolved from nursing practice. In many areas there is a significant overlap in what nurses and therapists do. As well,nurses are there *2k* hours a day uhereas therapists work usually five days a week.

What is nursing? A good definition is: nursing is the difference between what *a* patient should be doing and what they are able to do. The definition I like best is: nursing is that w occurs when a patient and a r interact. This describes the w physical, emotional and spiri relationship that can go on.

What are the main features of a nu care plan for an IN patient? predominant theme is assessment. A pa once said to me that he got fed up people asking "How are you?". But it crucial issue for the nurse. [i;]^fe getting better or worse?" Sometimes w make an objective assessment - "Yest he was able to get up and vette tSKeUoflet unassisted U-'t toi^Y g he UfsSfeady and

- and so tf\lkk
fetv" on your

Itvj about KCWJ you ^re dAd vJVLT=t"it ca annoying, even inf uTi^t^g-, to times a day by 24- different ' " • w

you §re feel--_ &AQ you K^[c]'/ \j\.q dfa a lot than yesterday your res is really important.

The worst scenario is th-ftt a p could require ventilation. The c *\j!£.* cjet to that point where the pati ,\o longer be able to support respi function satisfactorily the more w going to ask "How are you?" and the interventions and assessments are to be made.

The scenario next to ventilation i patient aspirating - the conten your stomach or secretions you been clearing ending up in

The O'.ner concern in assessment i the more interventions we have to do more drips and tubes we have to pu as well as being obviously unpleasa sometimes very painful, they also in the risk of complications. So if head thinqs off, we are often on ahead. If you visit IN patients support capacity, helping the understand why nurses focus on wheth patient is better or worse is impo

Sometimes the assessments ar formal such as when making measureme how quickly and how much air a pati expel from their lungs - a good ind as to whether a patient is

getting closer to needing support and ventilation or is getting better.

Sometimes it is very informal like a patient explaining that yesterday they could complete a task and today they cannot. Although it may sound trivial such as not being able to hold one's arm up^ clean the teeth^it is important and we are interested.

Sometimes the staff don't know what you are trying to tell them. As mentioned above, not all staff have had the necessary exposure to this relatively rare disorder.

In assessment in the acute phase -GBS - uie are also very concerned about traditional parameters such as blood pressure. Part of your autonomic nervous system controls blood pressure. Some of these involuntary bodily functions can become quite unstable. You can have very high rises in blood pressure that can be life threatening.

I encourage you to discuss and to validate all the laboratory results, the chest X-rays and the endless blood tests. They are of value but only if validated by what the patient is experiencing.

The respiratory assessment, especially during GBS in the first one to three weeks, includes vital capacity (how much air can you expel from your lungs), what your lungs sound like - as you get more tired you compensate by just breathing off the top part of your lungs and then the bottom part can fill up with secretions and get infected and you can end up with pneumonia.

Sometimes even the subtle assessment of just looking at a patient breathing can give the nurse a lot of valuable information.

As well,we do a lot of clinical assessments such as chest X-rays or measurement of how much oxygen is in your blood through monitors on your fingers or even arterial blood samples to measure the carbon dioxide and oxygen in your blood. These are to give some idea of how close to needing ventilation or whether you are improving or not. If you have a temperature the primary concern is whether you have a chest infection.

One of the most crucial things is whether you can cough or not. Coughing is the way we look after our lungs. It is a very early indicator of somebody requiring more assistance through mechanical ventilation. It sounds bizarre but if somebody can't cough to command or is having trouble generating strong enough cough to keep their lungs clear this is sometimes an indication that nursing needs to take over.

The role of physiotherapy in respiratory function is very important. An anaesthetist who contracted GBS described in an article having a tracheostomy against his better wishes and having an absolute fear of having suction done by various people. There was some staff he felt very comfortable with, others terrified him because their technique was different even though his colleagues would tell him that it is only a tracheostomy and it is for your own good after all.

Suctioning through tracheostomy is a technique in which some nursing and medical staff have not had a lot of experience. As in many activities, the more one does it the better one gets. It can be a frightening experience for the staff as well as the patient to have this done.

There is also the care the nursing staff may be involved in^such as giving antibiotics for a chest infection and encouraging the patient to keep their chest clear as much as they can. Nursing is facilitating the patient, not doing everything. Sometimes there is an emphasis of wanting the patient to cough it up to the top of your chest and then we will clear it from there. This can be tiring and may need a strong rapport between staff and patient.

The next aspect is nutrition. Cost cutting goes on in hospitals and the food services are affected and a lot of patients are not impressed. Those who have experienced this will understand how important it is. Having to spend weeks and weeks having to face the same sort of food that is never the right consistency for what you need. IN patients with facial palsies or other cranial nerve problems - the nerves that also control our swallowing - can have difficulty in eating and chewing food. Unfortunately hospitals catering for a large number of patients find it difficult to provide the consistency of food that a lot of different patients require. Some days patients are able to manage quite well on thickened fluids, on other days they need vitamised food. A

hospital is there to .provide service but if you don't tell us what the problems are we find it difficult to work through it.

Tube feeding sometimes becomes necessary and that is a fairly horrible experience. As *a* student nurse one is encouraged to pass a nasal/gastric tube either on yourself or preferably on a colleague to experience what it is like. It doesn't hurt, just feels dreadful. Having to endure it for an extended time must be horrific. As well, they come out or they get misplaced or they are coughed up or get vomited up and need to be replaced.

Maintaining a patient in good nutritional state is very important, particularly if you are looking at a prolonged period of disability or inactivity. If nutritionally deplete, your skin won't heal as well, you lose muscle tone, you don't have as much energy, and you don't feel like eating. Sometimes it is good to encourage families to bring in food that is preferred or cooked at home. Most wards now have microwaves and fridges to prepare and store food. Also for families it is a way to feel involved.

Another experience student nurses are encouraged to do is to be sat down, blindfolded and be fed a meal by somebody else. It is horrible. You give up after about two minutes no matter how ravenous you are. It gives another good insight into what some of our patients have to go through.

Cranial nerve disability can also affect the patient's ability to communicate. If you have a tube doiun your throat that stops you speaking^ communication becomes unidirectional. One of the most frustrating nursing experiences is having a patient trying to tell you something and you just can't understand. Even if you can't understand the words it is not that difficult to understand the emotion the patient is trying to convey.

Some of the practical ways nursing staff can assist is to look at the continuity of the care being provided. Seeing the same face day after day can be very reassuring. Also after a period of time you get used to the way patients express themselves. For the first few days it can be difficult for a new staff member to understand somebody^ but after working for a shift or two . they sort of understand and can interpret better. Making staff who are good at interpreting patients available for other carers such as medical staff is important. It is just like mothers understanding what their children are saying.

When patients are so limited as to being restricted to a yes/no response -usually a patient who is almost unconscious - it can take a lot of ingenuity and patience for all concerned to find what it is you are going to use - a finger moving, a blinking of eyes, a head movement. From that you can build up to all sorts of complex aids. They can be not all that helpful because they take a lot of concentration and commitment on both sides.

Another difficulty that sometimes patients don't realise is that their facial nerve problems make lip reading very difficult. It is then better to concentrate on very short sentences. Rather than "I would like to tell you I am really uncomfortable at the moment probably because I have been lying here for four hours on my back" it is better just to say "back" and work on from that.

The last area is that of lack of mobility. If a patient lacks mobility a range of complications may ensue^ not the least being breaks in the skin. Little breaks can quickly develop into large pressure sores, which may require skin grafting. The longer you stay in hospital the more complications can be expected. So just moving around is very important. I suggest to people they just go home and before they go to sleep lie still without moving for ten minutes. Being completely immobile is incredibly painful and uncomfortable.

To prevent pressure sores you need to turn patients every two hours. That doesn't take into consideration comfort. The difficulty is that sometimes it takes two or three staff to move a patient and there are just not the resources to be turning patients regularly. Some hospitals are fortunate in possessing beds that have a motor unit. Also it can be painful for some patients to be turned so you have a dilemma.

The other good reason for keeping people moving either in or out of bed is that one's joints are affected by periods of inactivity. Also your musc-

les become flaccid; your feet may drop in a condition called "foot drop". This is where nursing and physiotherapy overlap. There is also differing views as to whether splints is good bad or indifferent to correct say "foot drop". As soon as a patient starts to get active movement, the muscles start to u/ork again even if not properly, then the general rule is to encourage the patient to use the muscles.

Plobility is also important for the chest. It needs an incredible palaver to talk a patient with flaccid muscles and all sorts of tubes to get out of bed into a chair, but the upright stance is a very good position in helping to keep the chest clear. Out of bed your chest expands, the posture is better, the blood pressure has to work a bit harder to profuse your head, the kidneys are better profused.

IN patients can develop quite marked sensory changes so sheets, blankets and clothing can be quite uncomfortable *so* positioning can be quite difficult or even painful. It is better to endeavour to control the pain rather than relying on painkillers.

Buzzer systems in most hospitals are designed to be used by young fit patients that have no problem in pressing them. Creativity can get round this. One way is for staff to negotiate: we will drop in every x minutes and to stick to that as far as possible.

Some of my staff are trying out non-pharmacological agents - herbal teas, essential oils, relaxation techniques, music, staff sitting in for ten minutes doing something else - to help patients sleep. The nights may seem very long when you can't move around to look after yourself.

In summing up., if I said that people involved in this could feel frustrated and angry, unsure and even very scared that recovery would not occur, would you think I was talking about the patients? I might be, but I might also be talking about the nursing staff. This is not a plea to say "Oh, poor nurses" but to help you understand that we are sometimes scared about the outcome too and not just reacting to it in bed 17.

My impression is that people who have had inflammatory neuropathy are incredibly brave and very resilient, they have been changed by the experience, they are very humane and resourceful, and I take my hat off to them all.

NEWS OF MEMBERS

A special welcome to new member GEORGE WILSY presently recovering from GBS at Fairfield. Those who read the "Herald-Sun" will recall a heading "STRANDED TOURIST MERCY BID" just before last Christmas. The tourist was GEORGE who languished in a Manila hospital for a month after being stricken with GBS. Dr BRIAN SPEED made the "mercy" flight to bring GEORGE back to Fairfield Hospital. GEORGE is making progress having recovered the use of his legs. We all hope it won't be too long, GEORGE, before your arms are similarly active. GEORGE has been visited bath by myself and also member ANDREW WOLFF, an ex GBS sufferer.

I publish below *a* report from VILMA CLARKE and letters from GREG GILLESPIE and GRAHAM BLANCK. As well as providing fine examples of IN support in action they give great encouragement to the activities of The IN Group.

Report Jan'93 NE Victoria IN Group

James rang me to ask to call in and see John Ward who had been admitted to the Wangaratta Base Hospital with suspected relapse of GBS. I called in the evening to find he had been flown down to Melbourne. He has now returned home and started work. One of the lucky ones. I visited him in Beechworth - he is young - 25 years old. He finds he gets very tired but has a most positive approach and would be very good to liaise in Beechworth. As he is very interested in the Guest Speakers for the Feb meeting have suggested that maybe he can have it taped. (Tape sent to JOHN, now a member. A report of KATE FIELDING's address is published in this newsletter.)

My next person to visit was a 78 year old lady, LUCY CHICK. It appears that 13 months ago she was discharged from the Melbourne Hospital - under Dr Hjorth - after numerous tests with his findings that she had an onset of GBS but has had no further treatment or visits. 13 months later she is returning because she still has pains in her legs from the ankles up and severe wasting. She gets pain then rests them for two hours and they are OK again. It only goes to her knees and she has a constantly dripping nose since her pains started. She feels neglected. Her .visit

back to the doctors (9/2) is under her instigation. (LUCY has since joined The IN Group. VILMA has since advised that LUCY is now fine.)

VILMA CLARKE, IN CONTACT Person.

(Best wishes, VILMA, for your check-up at the Austin starting 29/3. JAMES.)

LETTERS

L)e.aA.

7 hank you. vejiy much £0/1 organising a. good Ape.akeA. at. QUA. laJ>t evening, Kate certainly know heJi jcH and presented it very well., Al^o would you. pl£.aA& thank you*. tireJLe.AJ> wif£- Betty , f.or mothering iu> -4O weU. dusting the. evening.*

A couple of. item interjected me., confirming that, there. -u> always Aom&one. worAe. than myself.. 7o me~et Aome.one. who had re.cently lost a husband from QBS was humJLling, and to find that, two f.orms of. QBS had &&en identified from. the. suff&Ajers of. recurring attacks was surprising. I. was also interested to hear of. the. progress of. the. kegi^teA. at the. Alfred} this mutt Surely assist in overcoming the. trauma of. IN varieties,*

*On 12/2 I visited the DaAncun&jool Base. H.oApita£ u)he^ie. I WOA given the. nanue.A of. two £.oca£ doctor who deaJt with neufio caj>ej> bef.onje. twnAfjzst. to Bail-ajiat OA. fleM.ouMne. I intend uniting to them, introducing the IN Support scheme, and my^eJif.. Fly vi^it to S7 3-ohn of. Qod HoApitat WOA te*A p/ioduc£hje.. I fee£ that tocaJt docto/u> mutt pa^A theiA. pat~ientA on,*

On 19/2 I thall He. in BaMuAjaJL and w-Ltl viAit JLoth Bate, and St 3-ohn of. Qod I hope, to have.

have. aJLt>o Heen in touch with two

6 who know me. and wa-4 *ued. One. can onMj p£ay a waiting game. ffiom. now on,*

*7o you. Hoth, SLe.*t wJ-the.A and. hope. you asie. wejti. Again thanks, f.oi youn. dedication,*

IN CONTACT Pejv>on.

7h-u> Zett^M. it to confsum out con-vejiAation at. OUM. 4.aJ>i meeting that I had paid a vi-^it to two QBS at the ca^teJtn SuJLuAJL>>

FloAon&y' A Rd, To/te^t Hiil.

contacted &y Liz ft.andeJJ. who Lt> a physio theAapi^t at the. Centre, and atked could I caJLt and Ape.ak to thej>e. pe.op£e. and diAcuAA the-ui pn.ogiej>A and what waA aequisied to he&p them undesi- the. ie.couejiy piognej>A, Both pati&nJUi weA&. AO p£e.aJ>ed to 4e&. who had had the. tame. com.p£ainti took -60 weJL4. and ILe. on hi^> fjieti and enjoy ii-fe. JLike. any other normal.

my v-Lf>it I gave. them. UA& aJLout 7 he. IN (jroup and gave, them your name.. I do hope, that they w-iil contact you. Although they Hoth indicated they wouM like, to ILe. mem&jeAA they don t think they will ILe. aLle. to attend meeting,*

7hey are 10N<j ffuv&u<a ana rnyjuLj.^ HMTcR.

I f.ownd it m.oAi /lewoAding to He aAJje. to Ait and talk to thej>e. pe.ople. I am AuAe. that they op p/ie.ciated someone, taking the time, and interest in them,

qRAWn BLANCK,
IN CON7AC7 Person,
Nunawading,

FROM A PHONE CALL

Valma Wood, an ex Fairfield patient now at the Montgomery Hostel of the Caulfield General Medical Centre, rang and reported she was geeting on well, was joining The IN Group but couldn't come to meetings.

She mentioned she was getting great help from having her feet massaged once a fortnight - all she could afford. Massage worked when phsiotherapy did not.

BOOKS THAT CAN HELP

"No laughing matter" by Joseph Heller, famed author of "Catch 22", gives an understanding what it is to contract GBS. He developed the disorder some ten years ago and made an almost full recovery. I borrowed a copy from my local library.

"Cry of the damaged man" by Tony Moore, a medico now in charge of the Hampton Rehabilitation Hospital, was kindly lent to me by Alexia Rosengart-en, a nurse at the Alfred. Moore's story of recovery from a horrendous car smash from a patient's point of view with a doctor's knowledge and experience is a rewarding reading for the IN sufferer. A ppbk by Picador.