

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

PHYSIOTHERAPY OF THE IN PATIENT

From the address by BARBARA BURZAK-STEPHANOWSKI, Chief Physiotherapist, Fairfield Hospital, to the meeting of The IN Group 10/8/93 at 4 Alandale Ave, Balwyn. JHG

We deal mostly with GBS patients. We do treat some CIDP patients but this disorder appears more nebulous. Acute Stage

The GBS patients we treat at Fair-field usually have severe effects from GBS including respiratory difficulties. The acute stage is the onset with the person dependent on the respirator. Their breathing capacity falls and they need to be intubated. A tube is put into the trachea and connected to the ventilator and the patient given an appropriate cycle of breathing. This precludes any speaking.

In this acute stage we need to keep the lungs clear of secretions. This is done by deeper breathing, by hyper-inflation, which is not pleasant. You wonder whether somebody is going to blow your lungs up. This is called therapeutic bagging. A special bag is inserted in the air/oxygen line. When the bag is filled up, we push on the bag and ask the patient to help if possible by breathing. When the bag is compressed we let go and the patient breathes out.

We carry out four or five such deep breaths and this will occasionally cause the patient to cough. Coughing is a natural way of getting rid of secretions. Suction is then required to remove the secretion from the trachea because the patient cannot do it. If secretions are thick, 3-4mls of saline solution put down the tracheostomy tube will help loosen secretions and can sometimes trigger a cough.

All this is daunting to the patient who has recently become paralysed. But if not done the patient can develop pneumonia.

The next most important treatment at this acute stage is relaxed passive

movements. If you have gone from an active healthy person to being paralysed it is important to keep a certain elasticity. So we do movements through full range of joints as much as we can. Unfortunately many people feel pain in this so we try and temper this. With GBS the patient is fully conscious so it is very frustrating.

We have joints that have capsules around them, strong binding material with lubricating substance. If the joint doesn't get moved it tends to dry up and so stiffen.

Legs and feet may be put in resting splints when a patient is spending most of the time on the back so that the joints, particularly the ankle ones, don't distort. Patients are turned from side to side so they don't get pressure sores. If a patient is very thin and so has a susceptibility to pressure sores we use an inflatable mattress. Rehabilitation Stage

The Rehabilitative Stage is the hard-work one, when the patient has some minimal motor return - the patient is starting to sit up, has head control. It takes a lot of "blood, sweat and tears". We physios who has suffered with the patients - indeed we do even though we are often looked upon as ogres - tend to develop a sense of humour. When in doubt, laugh.

Rehabilitation is the process of helping the patient to gain optimal functional ability after this has been lost, partially or completely due to the illness. It implies a wholistic approach making use of various therapeutic techniques from many disciplines including occupational therapy, speech pathology, nursing, medical, social work, psychology, nutrition.

One of the most important factors in

the acute stage is information education. We need to educate you on what is happening, what is happening to your body, how you feel, that you are allowed to feel anxious and that your family, your carers, your loved ones, need to understand what is going on, need to have the positive motivation that the prognosis is good. This is very hard when you see mum with all sorts of tubes connected to her. Anything that dispels peoples' anxieties will help ultimately the healing process.

The principles of rehabilitation we follow are assessment - initial and continuous.

There is goal setting - short and long term - set in collaboration with the patient.

There is the need to appoint a case manager so that there is one person to communicate with the family etc to prevent confusion.

The psychological well-being of the patient is very important. Any body trying to help - remember the physio is not healing the patient she/he is the catalyst - has to have empathy with the patient. People know that medication may be good for them but it is hard if they feel it is too painful.

In the assessment past medical treatment is important - the drugs and analgesics used. So is the social history and what your pain is like.

The objective physio test is the ffluscle Chart. We have a muscle grading that goes from 0 (can't do a thing), 1 (a flicker), 2 (move the muscle a little more), 3 (move a limb against gravity), 4 (move against gravity and resistance), 5 (starting to become strong to 6 (full functional capacity).

All the muscles (spine, upper and lower limbs) listed on the chart are tested at the start of rehabilitation and the gradings noted with assessment date on the chart. The case quoted was of a patient admitted on 19/7. He had a history of 3 days of sore throat, painful ears and vomiting. On the 20/7 he felt a little better but two days later the oxygen level in his lungs dropped. He was admitted to intensive care with poor swallowing, poor cough, decreased sensation in his hands and thighs. He was intubated with a tracheostomy and the muscle chart was done on 22/7. He was fairly low on the cervical spine though his neck muscles weren't too

bad, the trunk was zero, he could do a little with his hip area but everything lower was zero except he could do a little with his feet. It is a classical picture.

He remained like this - fairly incapacitated - for four weeks. This is the frustration stage - I can't do anything, will I ever get better, this is terrible. You get used to the situation but you hate it.

During this time he receives passive movement stretches to the limbs and the trunk. This is to keep everything nice and flexible.

On 14/8 the upper limbs became stronger and he started to get active resistant exercises. He is a bit stronger in the neck, the trunk is not brilliant but is the major part of you and the muscles here need to do a lot. He is starting to get some strength in the abdominals but there is still not much in the legs. The hands and the feet are often the last to get better. He started on oral feeding at this stage - jelly, ice cream, apple puree. Also he was breathing off the respirator 30 minutes every hour, breathing for himself half the time.

We stand him on the tilt table. He is strapped to it and then the table tilted to different angles, eventually to upright standing. This gets weight to the bones. When you are lying in the bed all the time your bones get affected too, get weaker. At this stage he would have 20 degree tilt for half a minute. This also stimulates nerve endings.

By the 17/9 he had got to the upright position. At this stage we did the muscle chart again. We see things are really happening; we are getting 3s and 4s in the upper limbs and trunk and 2s and 3s in the lower limbs. The myelin sheath that has been attacked grows back at a rate of about a centimetre or so a week. The insulation gets restored, the nerve messages get through and the muscles start working again. Once the muscle works you can strengthen it.

He is now transferred to the rehabilitation ward. Once his trunk and lumbar spine are at grade 3 then we start sitting the patient up and standing him without the tilt table but with the help of a frame. Then the work really starts. They can sit up in a wheelchair but because they have been prone for so

long their backs can be very sore. For difficult cases, particularly with tall patients, we use a reclining wheelcha-ir. A tall patient may have his legs hanging over and the feet are very sensitive. There is the "sock syndrome"

a sore foot and leg right up to the calf area. Even lightly touching a toe can be excruciating. So you have to be careful. When sitting, the patient needs lumbar support. The patient is encouraged to propel himself in the wheelcha-ir. Rehabilitation means trying to give the patient back his independence. Some patients are naturally independent but others need encouragement to become confident that they know what is best for themselves.

At this stage the patient hasn't got to be lifted like a log any more. He can be "top and tailed" or possibly transfer himself or do sliding transfers from bed to wheelchair with the aid of a board.

By the 25/9 he can stand using a gutter frame - has gutters in which he puts his elbows to lean on and wheels so he can move along. More 4s are being developed in the muscles. They still need a lot of assistance and encouragement. Gradually he is progressed to the parallel bars. More control is needed here, using the wrists.

At this stage the patient is fed up, having been in hospital for a couple of months. So the patient is encouraged to have a half or full day at home, usually on a weekend when he is not having therapy. We try and show relatives how to transfer a patient into a car, send a wheelchair home. Often the occupational therapy group will have a look at the house to see if they can arrange any improvement to assist the patient.

At early October hydrotherapy was started. Exercises in water are much easier than on land. Also in water you get the feeling of independence. In the water you can walk. The warmth of the water has to be a minimum of 32 degrees and maximum 36. This warmth encourages relaxation in the musculature and improves motivation and confidence.

At this stage we get the patient to walk using the frame rather than in the parallel bar race. At this stage there is no longer any need for further muscle testing. We just do some subjective testing.

On the 25/10, about three months af-

ter admission, the patient was discharged, but to come back as an outpatient twice a week. Again this encourages independence - you can do things for yourself at home, coming back just to do more activity, to improve.

On the 5/11 the patient could jog slowly. The usual period for the immediate acute and rehabilitation stage is 2 to 7 months. The older the patient the longer it takes - we have had patients for a year and longer. This does not mean the patient will not recover full capacity. Presently we have a young patient who has recurring relapses, which is an anomaly with GBS. We also have peripheral neuritis with HIV. In March the following year we did a follow up assessment. The patient had regained full strength and with slight loss of sensation in both feet.

A patient who had GBS ten years ago come in as an outpatient four years ago when I started at Fairfield. He had been doing some exercises and wore splints to prevent his feet dropping. But the exercises were too strong for him and after assessment and a cutback in the exercises, two years later he had sufficiently improved so that he could play golf and walk without his splints for most of the day.

It is most important in poly-neuritis cases that you must not let anybody fatigue to the extent that they get exhausted. Unfortunately when we start to get better we all tend to do too much. If you get too tired after an exercise reduce it to half. By this you will get to know what is good for you. Conclusion

Physiotherapy in polyneuritis is very important in preventing stiffness, in enhancing the prognosis which is usually good - the expectation that you will get back to a good if not full functioning capacity. It has a long ranging perspective. We follow up our patients year after year. We are trying to catch up with all the ones before my time, trying to get improvement and provide education. Many people who had GBS many years ago who were treated in other hospitals were sent home in a very bad situation because it was not understood.

WE HOLD OUR FIRST AGM

I took the opportunity to publicise The IN Group further at the Alfred by getting an item in their newsletter "Group Press" (reprinted in this issue). Next Get-Together a Social

We hope to see you all at The IN Group Get-Together on Sunday 14th November at 12 noon at 4 Alandale Ave Balwyn.

This will be our end of the year social gathering. Details are in the leaflet enclosed.

The "IN Group" forms for V&N& disorders

Alfred staff have become involved with a new support group which has been established to provide personal support for patients suffering -> from nerve disorders, Guillain Barre Syndrome (GBS) and Chronic Inflammatory Demyelinating Poly-neuropathy (CIDP)/

Called the Inflammatory Neuropathy or IN Group, the group also helps research into these two disorders of the peripheral nerve system.

According to Director of the IN Group, James Gerrand, the Alfred staff involved include Dr Bernard Gilligan and Dr Richard Stark who are two of its patrons. Dr Bruce Day is consultant neurologist.

Sr Kate Fielding, charge nurse of Ward 3A, and Sr Trish Hooton, charge nurse of Ward 3E are on the committee.

Should any patient be diagnosed with having GBS or CIDP, please advise neurology registrar, Dr Mark Farragher, who will inform the IN Group.

*"Group X-Press" 27/8/93
Alfred Group of Hospitals*

A TRIAL OF PHYSIO FOR CIDP

As an outcome of the talk "Physiotherapy of the IN patient" and the initiative of Vilma Clarke, four member sufferers from CIDP - Vilma Clarke, David Ashton, Fred Hooton and James Gerrand - have agreed to take part in a trial of physio treatment as a means of improving their condition. The treatment is to be conducted by the speaker, Barbara Burzak-Stephanowski, Chief Physiotherapist of Fairfield Hospital, over the next few months.

Our Annual General Meeting was held on 10/8/93 at 4 Alandale Ave Balwyn as a preliminary to our speaker's address.

Some twenty attended and accepted both the Director's Annual Report and The Treasurer's Annual Report.

Elected unopposed for 1993/4 were Director - James Gerrand; Deputy Director - Ray Dahlitz; Treasurer - Norm Blyth; Secretary - Vilma Clarke; Committee - Graham Blanck, Sister Kate Fielding, Sister Trish Hooton. There is one vacant Committee position: so if you would like to have some direct input to the workings of The IN Group please contact the Director (853 6443) or the Secretary (05 221183).

COINCIDENCES STRIKE THRICE?

A couple of months ago I was in at the Alfred having my gammaglobulin intravenous drip when I was told that there was not only one but two other CIDP patients having this treatment in this four bed Haematology Procedure room. Coincidence number one, CIDP incidence being perhaps 1 in 100,000.

Then I noticed the face of the CIDP man alongside was vaguely familiar. He turned out to be a fellow engineer, Fred Hooton, who had been at Sydney University a year or so behind me. Coincidence number two.

Coincidence number three was that Fred is the father of one of our IN Group committee members, Sister Trish Hooton.

SHORTAGE OF GAMMAGLOBULIN

The supply of gammaglobulin - the preferred drug for treating GBS and CIDP sufferers - finally dried up at the Alfred Hospital. I was at the Alfred last week 23/9 and had been connected up to the saline drip before being told that Pharmacy had no gammaglobulin. I had been on short rations the previous fortnight - 24 instead of 30 grams - like some other patients under this Intragam treatment.

It seems that gammaglobulin comes from two sources - locally (and cheaper) from the Commonwealth Serum Laboratories and overseas (and much dearer) from Sando of Switzerland.

The IN Group is doing what it can to lobby the Federal Government to ensure adequate supplies of this vital drug.

JAMES GERRAND,
Director.

LETTERS

ENCOURAGEMENT FROM

ABROAD Dean. Dairies,

greetings -from London. I am sorry I did. not get to your meeting.

I an. e.ssenLially weU. and JLoung InternaLionaJi travel..

I think your commitment to this til-ness Is very very good. It takes a special person to commit. yourself, whole heartedly and the results one. also great. I only w-ish my timing was better because It' A an area that I Relieve I could glue great assistance..

fly health and stamina are
Improving

I wllA be lack In Australia. In 1994 and w-ill. fo-llow up on everything when I return,

Take, good cote. o-f. yourself, and please keep me Informed on the latest developments.

DAVID CHRISTIAN

London

(David is a chef in his early 20s who suuffered from GBS in 1991/2)

PARALYSED BY GBS 22FT

UP Dear J-omes,

Hove just teen admitted to the Royal Melbourne. Hospital, after suf.-f&rlnng yet another, setback. I was admited to the Uangaratta Bate. Hospital on 17/7/93 and I' m wilting to you from the. RflH on 23/9.

As In the setback In December I have a lot o-f. the tame symptoms (numb-ne.ss, pins and needles, crumps and pain) as I had when QBS struck me. In OctoHesi 1992.

This time, the InjLlamm.atl.on started not piom a cold Hut at wo/ik. I was working at Uodonga at the Uncle Ben's fac-io/iy on sca-f-jLoldlngi painting /tol&esL dooas aHout 22 ft fiom the gx.ou.nd. At fuist I was a little apprehensive Out gained some confidence as this was the. •jLUist time, since going Aack to woik In 7e&Jiuajiy that I'd He.en up this, high on triesttes and a ptank. &£LeA. painting £01 aHout 1 1/2 housis we stasited to cllmlL down the scajLJLoldlng £01 smoko. It was then that I found I was stuck, completely fiiozen In one spot as I could not fieeJt anything faom my waist down.

Afiteji a shoit time, an extension ladder, was raised up to me. to help me down. At this stage I JLeIt like a mon-

key hanging on to a tree. Lnanch with my faet dangling as they liked. It took thfiee. men to pay my JLngeAS away piom the ladders as my gilp on the ladders had Increased, like a vl.ce' s grip.

I'm slowly on the Improve once again and they are doing the same, tests as Oe-f-ore (lum&.ar puncture, Mood tests and nerve testing) and o-/L course the very Important physt.0, 7he care at the RflH. and the WBH. once again Is great.

3OHMUARD

Beechioorth

AN INSPIRING

STORY Dear 3-ames,

I am delighted that the "IN QROLLP" has been established as a support group for QBS and CIDP su^erers.

fly -father BUJ. Knight was diagnosed with QBS In flay 1984. nl.s was a severe case, spending 11 months In I.C.LL. at the Repot Hospital and another year at the Caulfleld Hospital.

He -is classified as a quadraplegtc as he only has HmULed movement o-f. the upper ILody. He also has a permanent tracheostomy.

fly mother cared for him at home until, her death In flarch last year.

Placement 0-/L him was an enormous problem as he had special needs. However, a-jLter weeks o-f. searching and with no real assistance, I came across Si 3-udes Nursing Home In Chadstone, This Is a home, for wheelchair people..

Over the past nine years, my father has remained very positive towards liJLe, He. I^ an avid reader and has a great Sense, o-f. humour. He. adores his -/LamULy and they adore him. He takes a keen Interest In his grandchildren s sport and when possible we take. him. along, fly father comes home to me two or three, days a week and to my sister's on the weekend. Ue try to give him as normal, a LijLe as possible.

Although It -is a terrible UJtness, Lijje can go on,

I wl^h you weU. with your group and I would, be delighted to assist In any way - I have had lots of experience!

(flrs.) PRU£ CROXFORD

Burwood

TRIBUTE TO BARBARA AND

FAIRFIELD Dear flr. Qerrand,

I do appreciate receiving the IN Group Newsletters and have learned much about the InfAammatory Neuropathies

from reading them,

Unfortunately, I shall not be able to attend the August meeting as I will be in Queensland. I am especially disappointed as Barbara Burz, aka Stef. anowski, will be speaking. Having undergone intensive, physiotherapy and occupational therapy for two months at Tairfield I was in constant contact with her. As you know, she heads a very dedicated team whose patience, understanding and encouragement/ not to mention their professional skills, are responsible for me reaching my present stage of recovery. Indeed I owe my life, to the dedicated doctors and nurses at Tairfield.

I hope, that I will be able to attend the following meeting towards the end of the year, if you are short of assistance, with what you term the "mundane, work" of the group I would be happy to help on my return from Queensland.

Lowry BRENNAN,
CamHerwell

Support for young man ujjh

GB5 Dear Barnes,

Many thanks to you and other people in the IN Group, especially Heather (mother of member Chris), for all your help over the past few weeks, I'm sorry I can't come, to your meeting on Tuesday night as I'll be in Ward 3 A at the Allied with Tom (21 yr son).

After his 3 weeks in Intensive Care, he moved up to 3A on Monday 2nd and on Wednesday the tracheotomy was taken out and he has been talking clearly since., We are all delighted at this rapidly improving development of movement and/or motor skills. There have been very few 'down days, one of them more, connected to Collingwood's temporary fall last week from the final six..

My own anxieties in those, early weeks while, he was on the respirator were, greatly allayed by the information and support I had from the group, The staff of 1A in I.C.M. were, simply the best and I have, complete confidence in Jillard Starke and Frank, the Neurological Registrar at the Alfred who diagnosed QBS early on that Tuesday 13th

3-ly_

John is in great spirits, taking a wryly humorous view of much that goes on and confident about making a complete recovery, The temporary paralysis of

his body seems to have, sharpened his mental faculties - some time I'll tell, or he will, about the funny and sometimes risqué things that can happen in hospital when you need to ask to be scratched in odd places,

I am happy to be of any assistance to patients and parents and look forward to meeting more of you.

Finally, as a non-medical but committed observer, I have a range of suggestions and theories about QBS and its treatment and patient management.

Well everyone the Alfred is a great place and Hest wishes for a successful evening.

clwood

NO HOLIDAY FOR GBS

SUFFERER Dear Mr. Qerrand,

I am writing to you on behalf of my husband Niklaus (Klaus). Thank you very much for the newsletters and information, which we both found very interesting reading.

I thought you might be interested in the course his illness has taken,

On Sunday 23rd May, we were ready to leave for a holiday in Malaysia. On the Saturday Klaus had complained of having tired legs and feeling a bit tired. Thinking he might have caught a virus or something he went to see his doctor. She could not find anything wrong, saying a holiday was probably just what he needed.

On Sunday morning he was feeling about the same, just a bit tired in his legs. Nothing that 2 weeks in the sun would not fix., we thought! But on the flight he got suddenly worse and on arrival in Kuala Lumpur eight hours later he had difficulties in walking and was feeling extremely tired all over, The next morning he could barely walk to the bathroom unaided, had no appetite and was generally feeling very ill. The hotel doctor could not find what the problem was putting it down to fatigue, yet I knew it had to be something more serious,

The next day, Tuesday, Klaus was unable to get up from the bed and stand on his feet. We were now really worried and I arranged for him to be taken to hospital. After all the usual tests, which showed nothing abnormal, the neurologist also arranged for scans of the spine and brain and again everything

was normal. So what waA wrong, i&e. ke.pt asking ourselve.s?

It was now 7huA.Ad.ay and Klaus had He-come. worse. eveAy day, fie. couJd now not move. his le.gs at all, could not tuAn in bed. and hit also had He.come. veAy weak, tie. was una&le. to eat and was put. on a glucose. drip.

He. had a tot of. pains, e.Ape.cially in hiA (Lack and weird sensations -in hi.s le.gs and to some. extent also in hi* arms, Had CAamps, pins and n&edl&s, num&ne.AA etc.

In the. meantime. I had contacted QUA Travel Insurance., who were. mo At helpful and made. arrangements to fly Klaus back to nelHoume., As he. was unaHle. to walk, he. had to He. accompanied Hy a nurse. or doctoA f.or the. Airline. to take. him' aA-OOAd. 7he. Insurance. was OAAartging to send a nurse. oveA to KJL although with toying to get. -flights and eveAything it was now going to He. 7ue.Aday u/vtil we. could leave., T our agonising day A f.or

7 he. Neurologist had Hy now diagnoAed the. illnj&AA aA Quillain-Barre. Syndrome., The. treatment he. advocated at the. time. were. Aome. kind of. AteAoid taHletA, Plasmaphor&sis WOA ne.ueA mentioned, I tlaA it a lack of knowledge. oHout thJ^t> fo/un of. tAeatment ox. a tack of faciJLLLLlej>? We. don t know, aA we had nevest he.aAd a&.ou.t the. iJL£ne.AA OJL the. treatment, we couJdn t aAk aiout it.

7 he poAa&jAiA had now moved u.p to hiA fa.ce., he. had no JLaciaJ. expsi&AAi.onA and h±A Ape.e.ch He.came. AiLghtly ILtuAAed.

PainkiJUejtA and AJLee.ping pJJAA did not have, any e.£fe.ct, AC he. waA constantly in pain and couJd not get. any

7 he. AteAoid taJULetA had aJt&o made. him veAy A-Lck and the. doctoi stopped them., fiiA Ltood p/Le^AuAe. waA high (Lut he. -jLound it. veAy dif.£LcuJtt to Awa&low the. ta&JjetA he. waA meant to take..

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at the Lpwoth, K-tauA WOA tn.anAf.eAAed to the Royal nelSLouAne! A Intensive. CaAe UniJL

7he. Aame. night he. waA hooked on to the. machine. f.osi the. f.iAAt treatment. He. alAO got a noAal gaAtAO tu&e. aA he. had-n' t eaten f.0*. a we#k, 7he. next day he. WOA fueling Alightly moie. comf.o/itaile. and afJjeA a f.u/itheA ptaAma exchange, (of. whi.ch he. had a total of. 5 on alteAnate. dayA) we. could ASJH the. -fiiAAi improvement, tie. could wA^Lggle. hiA toeA!

T/iom theAe. on he. continued to improve and on the. 5th day he. lef.t I.C., and went to the. woAd. He. now had hiA daily phyAi.o routine, and the. doctoA weAe. pleaAed with hiA progreAA. He. could now Atand f.or Ahort moments and af.teA. 2 we^kA WOA a&le. to walk a few Ate.pa with help. He. WOA now iAonAf^AAed to the. Donvale. RehaJLiliation HoApital where, he. continued to improve.. It waA alAO cloAe. to home, which made. it. eaAi&r f.or me., K~iauA walked now on a frame, and after a f&w more. dayA on a Ati.ck. After reading a lot about thiA iHne.AA we. re.aliz.ed how lucky he. was to have, recovered to Auch an extent in a relatively Ahort time.. After a total of. Aix weekA he. came home and went f.or phyAi-otherapy OA an outpatient 3 afteAnoonA a we^k. He. Atarted to go f.or Ahort walkA and took up hiA Awimming again, only Alowfy of. couAAe., OA anything AirenuouA made him veAy Lired.

It iA now ne-arly 4 months and he. has good days and Had dayA, Although, thank god, the. good periods seem to get longer. He. just had 3 veAy Had dayA, the. worst since, he. lef.t hoApital. It iA frightening, aA we. know there, is always the. chance, of. a relapAe.. But he. ±Af&e.-ling a Hit Ajetier today and we hope, he will He. lucky enough to completely recover eventually.

It might inieAest you to know that KlauA did not have, any viral infection pre.ceeding his illness, Hut did have, a He.paLiLiA A shot the. we.ek He.-fore. we. went on holiday.

I enclose, a cheque, and we are. looking f.orward to the. next newsletter and wouM. also He. interested in attending a meeting,

SILVIA & KLAUS QWB
cast DoncasteA