

INFORMATION

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

Occupational Therapy for the IN Patient

From the address by LU CRAVEN, Occupational Therapist, Fairfield Hospital, to the meeting of The IN Group 8/2/94 at 4 Alandale Ave, Balwyn. JHG.

Our treatment of both GBS and CIDP patients is similar except that with the chronic condition we have to be more careful about not tiring the patient.

Occupational therapy occurs over three stages in the patient's treatment. The first stage is for those who are in intensive care. Their respiratory problems will need assistance with ventilation. A particular need is to minimise damage to the soft tissue structures through upper limb splinting. Usually both arms are placed in a resting splint so the patient doesn't get any contractures or deformities while unable to use their limbs. The therapist makes a customised splint to suit each patient. If the patient has active finger movement then we make a wrist splint. If the patient has a swelling (oedema) of the hands then we will make lycra gloves. We introduce hand strengthening exercises through providing therapeutic putty or sponge balls.

We also carry out a passive the daily ranging of all hand, to prevent joints of forearm, contractures. The elbow and shoulder work in a similar joint deformities and physiotherapists also way.

We try to improve the patient's quality of life while in intensive care by setting up reading frames with large print books, a page turner or talking books. We give psychological and emotional support to the patients and family members. We provide education about the disorder process and encourage the patient to bring in photos and objects from home.

To help pain management we introduce relaxation with individual sessions or the use of tapes. We encourage reality

orientation. When in intensive care the patient does not know whether it is day or night, or the day of the week. We would set up an orientation board with the day of the week, month and year. We encourage them to watch the news on television so they can keep up to date with current affairs.

Whilst a patient is on a ventilator, it is very difficult if not impossible to talk. So to make needs known to staff we will set up a communications board upon which a patient can spell out a word by pointing to the letters or else point to a picture. Alternatively we can use an electronic communicator with the patient pushing keys to spell out a message to staff or family.

A patient may be in intensive care for a few days to many months. He or she will then be transferred to an acute ward and then on to the rehabilitation centre. During rehabilitation the patient will receive intensive daily occupational and physiotherapy. He or she will tire very easily so we have to be careful not to over-tire. To begin with we take a full medical and social history of the patient. Then we do a range of physical assessments: standing and sitting tolerances, hand function, grip strength (using a dynamometer), pinch (using a pinch meter), sensory function (determining sensory loss).

In the treatment stage while each patient is in a standing frame which the physiotherapists have arranged he or she is given activities to encourage return of function, including strength, co-ordination. It is a combined process - the patient is able to increase their standing tolerance while doing an activity, such as for example, writing.

If the person cannot grasp a pen for writing then we will provide an adapted grip for the pen. Patients with no power to lift their arms may need assistance through use of the OB Help Arm for activities such as eating or gardening. Cutlery may need to be modified.

Balance boards are used for restoring capability to balance, lost through weakness of muscles. This restoration is necessary before regaining walking ability.

We teach patients independence in activities of daily living (ADL). People often have difficulty in transferring from a wheelchair into a bath or bed so we have an adapted bathroom where we train patients how to get in and out of a bath. Toilet seats* may need to be raised. It can be a big effort to get up from a low position.

We encourage and teach patients to get back to managing at home. Part of this process is cooking. We demonstrate alternative methods of doing domestic work and instruct in principles of work simplification and energy conservation. We provide devices such as jar openers to help. Group activities are encouraged. Pottery is a particularly useful and popular activity. The resistance of the clay strengthens the hand muscles. Computers may be operated with a finger or a head switch.

During treatment the psychological approaches of relaxation, stress management, counselling are covered with close liaison with the Social Worker, including achievement at basic activities to increase self esteem and confidence.

We assess the patient's ability to do other domestic skills - washing, ironing, laundry - to determine capability of coping when he or she goes home. Sometimes it may mean teaching the patient another technique to suit the disability.

When the patient is ready for discharge it is generally an anxious time for the patient and the family with worry about whether the patient can cope. It is often a time when the patient has plateaued, they haven't returned to their full functional ability. Sometimes a home program needs to be organised so that they come in as an outpatient for treatment at a hospital,

community health centre or day hospital in the area.

The O.T. always goes home with the patient to assess the patient's ability to manage at home and whether any modifications to the home is needed such as rails or the loan of a toilet frame. As they regain strength at home they may not need them further. We may need to recommend a nurse (RDNS), Home Help, Meals on Wheels. Sometimes the home visit may demonstrate that the patient may not be able to manage at home, particularly if they are on their own. Alternative accommodation may need to be organised.

We also assess the person's ability to return to work, whether they can go back full time, part-time or voluntarily. If return to work is not possible then other options will need to be explored. A visit to the workplace may be needed to assess the person's task performance at work. The O.T. may need to negotiate with the employer and patient to formulate a graded program for returning to work.

The O.T. will look at leisure activities. We may advise on leisure options and investigate community activities and some leisure equipment may need to be adapted.

The O.T. is also involved in driver assessment. Once a person has suffered a medical condition which changes their physical status, a medical report needs to be submitted to the Road Traffic Authority. So the O.T. is involved in assessing the patient's physical, cognitive and psychological ability to return to driving. There are computer simulation programs to assess a person's reflexes and reaction time. A computer can be used to improve these if needed. There are specialised O.T.s in Melbourne that do these assessments. Such an O.T. is involved with liaising with the doctor in completing the medical report for drivers and including an O.T. report if an O.T. reassessment is necessary. The O.T. may make recommendations for hand controls or other modifications.

Basically we try and make the patients as independent as possible, improve their return to function and make their life a little more interesting.

Collingwood's shy champion breaks his silence over the mystery disease that almost ended his football career

The fright of Wright's

EXCLUSIVE

By SCOT PALMBERG and SUNN McFARLANE

FOUR months ago, Collingwood champion Graham Wright could barely utter a single word. Yesterday, it was a battle to keep the normally reticent Collingwood wingman quiet as he expressed his joy at recovering from a mysterious viral illness.

The 25-year-old Magpie was told by his specialist on Wednesday he had beaten the rare Guillain-Barre syndrome, a disease that has been baffling doctors for nearly 300 years. It can leave sufferers with long-term paralysis.

Toe doctors have told me I have made a complete recovery," Wright rejoiced.

Rejoicing too are his coach Leigh Matthews and his Magpie team-mates who had been fearful Wright would never be able to sprint and weave his football magic again.

He had contracted the syndrome after falling victim to a glandular fever-type illness, unaware the disease, which strikes only four in 100,000, existed.

"It was (lightening, said Wright, who lost his speech. nas unable to drink or eat. couldn't close his left eye and had his face stretched to the point where he couldn't find a wrinkle.

After just nine days he was in a wheelchair, helpless and fearing the worst. His weight dropped from 82kg to a dangerously low 70kg.

Further deterioration would have seen the 1090 Brownlow Medal runner-up face the ordeal of a blood plasma transfusion.

Fortunately, Wright's case was of the "mild" variety and he has now become the shining light in a foundation for sufferers of the once deadly complaint.

"It was an enormous relief when the doctor said I'd recovered," Wright said.

The thing attacks your nervous system so they want me to delay starting heavy weights.

"That's fine" by me. I'm just grateful to be back on my feet and well again."

Now, amazingly, Wright plans to play with the Magpies when they take in their first AFL match against Fitzroy on March 26.

That seemed an impossible dream when Wright first

felt the dreaded symptoms last September, just days after Collingwood ended its 1993 season with a loss against Adelaide.

Wright did not play but went to Adelaide with the team before going home to Tasmania.

It was there he noticed his feet were numb when playing basketball with mates.

"It was a little strange but I just put it down to a bad back," he explained.

Still, the star Magpie had foresight to call the club physiotherapist and was told to immediately consult his doctor in Tasmania.

"They seemed to think it was some virus but they weren't sure," Wright said.

Wright's decision to go with his girlfriend Tracey to the Northern Tasmanian Football League grand final between Scottsdale and Ulverstone did not help.

"When I was walking up the grandstand I had a jumper around my waist. I was going carefully because my legs were unsteady. Then the jumper fell," he said.

"I just looked down at the jumper. I tried to pick it up but I couldn't.

"I fell into a bloke and just grabbed hold of his shoulder to stop falling."

Fearful of injury Wright stayed with an anguished Tracey in the grandstand until the game finished.

"I was embarrassed as hell because I thought some people would think I was pissed or something like that. I didn't know what was wrong with me."

His condition deteriorated until he could barely walk. Collingwood urged their star to return to Melbourne for treatment.

He was helped on to the plane by his worried mother, Elaine, and on arrival immediately checked into Warringal Private Hospital in Heidelberg.

But he kept losing weight. "It was brought on by a glandular fever-type illness, that's the reason why I went off my food and lost so much weight.

"I couldn't close my left eye and all of the wrinkles on my face dropped."

"Then Shawnie, Brownie, Stare ... a few guys came in to see me. I couldn't tell them to go away.



Cometocci: relieve / WrigW -)»* «raMM to b. wdl 090*.* Pctim; DAVID GERAGHTY

"But it was hard. I didn't want to see people because I was feeling so sick."

Finally, a team of specialists diagnosed Guillain-Barre syndrome while Wright was still bed-bound.

Soon, Wright started to get feeling back in his legs.

"I was lying on my side in bed when one day after about two weeks I was able to lift one of my legs. It was a great feeling."

The first steps you take are amping," he said. "It's like walking as a kid."

That was the same week Wright's doctors gave him some information on the syndrome and he learned how rare and threatening it was.

"They waited until I started to show improvement before they gave me some literature on the syndrome. Tint was probably

wise on their part. Some of it reads scary.

Thankfully, his recovery proved reasonably swift and he was able to leave hospital after three weeks with instructions not to start running until Christmas.

"I went home to Tassie and as soon as I got home to Mum's, I started to feel a lot better," a grateful Wright

Graham fright joins The IN Group

When I learnt from the press that Graham Wright had contracted GBS I tried to contact him personally to offer our support service. The best the Club would allow was my sending him our literature. Then a month later I had a ring from his doctor asking if The IN Group had a member about Graham's age who had made a good recovery from GBS. I contacted Chris Hagerty who kindly contacted Graham.

his help "in any way possible. Visiting kids in hospital with GBS I've given a lot of thought to. I would love to visit and give as much encouragement as I could." I immediately sent off a letter to Dr Shield, Director of Neurology, Royal Children's Hospital, enclosing Graham's offer. Thank you Graham and we are all pleased (even this die-hard Essendon supporter) that you are back in football fettle.

Proposed Epidemiology Study

This study has reached the stage of the questionnaire being finalised by our consultant neurologist, Dr Bruce Day, with the help of our consultant epidemiologist, Dr Allan Christophers, and approved by Patrons Prof Jim McLeod and Dr Bernard Gilligan.

The procedure will be, firstly, to ask our members to volunteer to be interviewed by one of three (to spread the workload) interviewees - Betty Gerrand, psychologist; Graham Blanck, IN Group committee; and myself, Director. An initial group of 25 will be interviewed and then the results examined to see if the questionnaire needs revising.

I have enclosed a form and a stamped addressed envelope to be returned by a member who has suffered from GBS or CIDP who agrees to take part.

I look forward to your support in this way for our study.

Intragam Research Project

Our consultant neurologist, Dr Bruce Day, wishes to investigate why Intragam (the intravenous injection of gamma globulin) is so effective in restoring muscular strength in some sufferers of GBS and CIDP in a matter of days or even hours..

Dr Day would like those members who so benefit and would be interested in taking part in his study to return the enclosed form. Dr Day will then explain to those interested what would be involved.

IN Group News

Membership

Membership is now 111, again a steady if small increase over the past three months. Our latest member is John Stanley of Devonport who is making every effort to start a Tasmanian Support Group. I told him we will give him all the help we can. I began by sending him the past 5 issues of our newsletter.

Some members have still to renew. A form is included for those who may have overlooked. The IN Contact Network

Member Damien Beasley of Shepparton quickly responded to my contact as his letter relates; "It was gratifying that both you and

the social worker of the Goulbourn Valley Base Hospital (Shepp.) felt that you could call on me to visit." "Firstly Mr Eric O'Brien, 72 y.o. semi-retired farrier of Mooroopna who has been hospitalised for 8 months ...and received 7 treatments of plasmapheresis (PP). Eric was bowled over quite quickly with GBS. He had just finished re-shoeing 4 horses and about to feed out hay to the stock the next morning but had to ask his wife to finish off.."

"The other GBS patient at the hospital is Mr John H Eldridge (59 y.o.) of Murchison who has over 30 years of service with Telecom. John like all GBS sufferers was initially shocked when he stated losing strength in Dec '93. John said 'He wouldn't wish it on his worst enemy.'"

"Both Eric and John had never been seriously ill and were still very active right up to being struck with GBS. So they were both overwhelmed to see me so 'fit and strong' after having suffered two severe onslaughts (neck to toes, Oct '81 12 months & Nov '88 1 month with 5 PP at Fairfield). I am 35 y.o., a father of 3 daughters, married to Joan 10 years and teach P.E. etc at primary level."

"Eric and John have just been released in recent weeks and are receiving rehab once per week. They are keen to keep in contact with me and The IN Group." "I have left my name as the local I N Contact Support Person and am endeavouring to rally up some more local support for plasma donors." "PS. I am very keen to meet other IN members later in the year when/if we have another daytime meeting..." Yes, Damien, we look forward to meeting you.

Then from Ern Kearley: "... I called into Hampton Rehab and had a chat with Laurence Lonsdale . The GBS has mainly affected his hands and feet and he is need of a wheelchair. I think he appreciated our little chat. I also met Barbara Weir, the Senior Social Worker, and told her about our Group, leaving some of the literature." Finally from a postcard from NZ "As a member of The IN group ...I think of you often and thank you for the information I receive. ...I will be in there as soon as I return. BILL MILLER."

See you all at our next meeting, Tuesday 10 May «po 4 Alandale Ave Balwyn. -T.3C