

INFORMATION

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

Care of the Feet for the IN Patient

From the address by AMANDA CRANE, podiatrist, to the February meeting of The IN Group, held 14/2/95 at 4 Alandale Avenue, Balwyn. JHG

Previously podiatrists were known as chiropodists but now podiatrists qualify through a three year degree course. We treat anything from the ankle down. We are employed in a number of different areas - hospitals, day hospitals (of which I am a part of), community health centres and private practice.

To see a podiatrist at a private practice you don't need a doctor's referral but some hospitals and day centres do, just as a way to screen patients. Unfortunately at the day centre I work, Mt Eliza, there is a three months' waiting list so therefore we do try and screen patients.

If you qualify through the Department of Veteran Affairs you are entitled to receive podiatry through them - I think it is six free visits per year.

Common ailments

One of the commonest is the CORN. Corns can be very painful and generally occur at prominences such as the little toe. You get pressure marks from the shoe rubbing on the prominence that results in a corn. There is another sort, often misdiagnosed, which develops between the toes. If you have this problem it is likely to develop in hot weather when your feet sweat. The usual treatment is surgical excision by a podiatrist (we remove with a scalpel blade).

You can get corn pads and corn cures from the chemist but keep in mind if you have any circulation problems or suffer from diabetes please refrain from using them. They contain quite strong chemicals and, rather than removing the corn, can cause irritation around the area.

The second most common complaint is the CALLOUS. They usually occur underneath the foot, due to shearing pressures. They are also usually removed by the scalpel blade.

Unfortunately with both corns and callouses, they will come back unless the problem of the bony structure underneath is addressed. This is where podiatrists have a big role to play that we love to make devices. Such devices worn in the shoe take the pressure off the affected area and redistribute over the whole foot. As a result your visits to the podiatrist should be less frequent.

Other things you can try at home for callouses are Dr Shell's products. Some are quite good. One is a pumice stone which you use to abrade the callous in between visits. They tend to work better after a shower when the skin is moist.

Then there are BUNIONS. They usually occur under the big toe. They are not caused by footwear but by an inherited bony structure. Improper footwear, such as high heels with narrow toes, can increase the rate at which they occur.

Over the top of a bunion can be a BURSA which is a fluid-filled sac. On hot days or when wearing shoes that are too tight, that fluid-filled sac will inflame and that is when you get your bunion trouble.

Then there are dry, cracked heels usually due to wearing thongs or sling-back sandals. If you have circulation problems or delayed healing then you have a perfect environment for infection.

If you use a moisturiser on your feet it is important that you use it

regularly. Two good products are Cal-muric Cream and Sorbaline Cream.

People often come to podiatrists with foot pain. They may have been to their doctor and told they have a spur or they have just got this pain that has gone on and on. Finally they come and see us. What we often do then is have a look at how they walk, often using a video camera, and then assess whether they need orthoses, often previously called arch supports. They are custom-made devices to fit your foot type that go into the shoe to support the arch for those people whose arches have collapsed. They control the movement in the foot.

We see many children these days. There are children who walk with their feet partly rolled which puts a lot of strain on the legs and the muscles of the lower limbs. They may need some orthotic device to overcome their rolling gait.

Footwear

Footwear is a huge problem. Factors to keep in mind are: (1) buy leather shoes because synthetic shoes don't allow the escape of water vapour; (2) high heels and sling-back sandals are a "no-no" (high heels also move your centre of gravity forward, putting your body weight on to the front part of your feet, causing excess pressure and resultant pain); (3) lace-up shoes are better than "slip-ons" because the foot is more secure and does not tend to move around to produce callouses and toes to "claw".

People with disabilities can get shoes to suit through going along to a day centre after a doctor's referral. They are provided by PADP and are often custom-made.

Problems of neuropathy patients

With neuropathy you sometimes cannot feel pain so it is important to have a good look physically at your feet each day, including under your feet. Standing on a towel is not good enough.

Also it is important to have your feet checked from time to time by a podiatrist, say every six months if you have no particular foot problems.

Particularly in hot weather it is important to dry thoroughly between the toes to avoid tinea. If you have difficulty getting down to your toes get a 30cm ruler and tie some towelling

around the end.

Insoles can be helpful by being shock-absorbing provided they don't flatten out.

Feet will swell during the day, particularly in hot weather. This is particularly so if your leg muscles have been affected and fluid tends to collect. This is why you should buy shoes in the afternoon. Also you may need a wider fitting than is available in the normal shoe shop but there are shops that do stock the wider fittings.

People with foot-drop need to consult the specialist prosthetist, the orthotist, who will prescribe the appropriate splint to keep the foot up and so help walking.

Medicare does not cover podiatry. People with health cards can get a slight subsidy. If you are privately insured you should check whether it covers podiatry.

When cutting toe nails try and cut straight across. This avoids ingrowing toe nails. Also don't cut them too short. Cut them after a bath as the nail is then softer. If you have really tough and thick nails (rams horn nails!) you probably need to see a podiatrist. You can try filing them first, an electric drill with a grinding attachment can even be used.

There are many different types of nail scissors. Some find the type with a lever action helpful. One member reported that the scissors on his Swiss knife was very effective.

Fungal infection can easily be picked up. One ointment named Lamisil has just come on the market and is very effective but it needs a doctor's prescription as it is expensive (\$80 a tube). There is also Gordocho Solution which is quite good and available from the chemist.

(Chronic inflammatory demyelinating polyneuropathy)

A short guide for the patient,
relative and friend

This helpful guide, produced by the Guillain-Barre Syndrome Support Group of the United Kingdom, is available, \$2 including postage, from

The IN Group
138 B Princess Street
KEW VIC 3101

Study

The results of the epidemiology study of 29 sufferers from GBS (19) or CIDP (10) who agreed to be interviewed are now being examined.

The study reaffirmed some understandings. The onset of Gbs was likely to have been triggered off by either flu (9) or gastroenteritis (7), The onset of CIDP was much less clear (2 flu, 3 gastro).

Another significant difference was that the therapy used for GBS sufferers was mainly plasma exchange (11 out of 20) whilst with CIDP the treatment was more mixed and varied - 8 steroids, 6 plasma exchange, 4 Intragam, (out of 24 used on the 10 patients).

The age of onset tended to be grouped above 50 years - 15 out of 19 for GBS and 7 out of 10 for CIDP - but this may be a bias due to older people being possibly more inclined to join support groups.

Some negative findings were clear. There was practically no family or past history of GBS or CIDP, nor was there any connection with a listing of 21 diseases.

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The proposal to use a hospital's computer system to advise a patient when diagnosed as to what support group may be available has received acceptance in principle by the Alfred Hospital Medical Administration. We are now awaiting the wheels to turn to place it into operation. The Head of the Alfred Neurology Department and IN Group Patron, Dr Bernard Gilligan, has been helpful in the negotiations.

IN Group Postear

We now have an eye-catching A3 size colour poster to publicise the existence of The IN Group.

A professional artist was commissioned to create it. The artist's background as a nurse helped her realistic depiction of half a dozen experiences that may befall GBS and CIDP sufferers - intensive care, wheel chair, hydro-therapy, electrical testing, Intragam treatment and an IN Group meeting .

The laminated posters have been well received by the medical and nursing staff at the Alfred Hospital and already adorn the walls of its EEG/EMG Department, Haematology, Procedure

We now hope to distribute copies through our Contact Members to other Melbourne major hospitals.

If any member would like their own copy they are available at \$5 (\$10 laminated) from

Director, The IN Group
138 B Princess Street KEW 3101.

with CSL

As a user of their Intragam product I was invited by Mr Jack Wood, General Manager Bioplasma, CSL, to address their staff at their Broad-meadow centre on 13/12/94.

I told the hundred or so at the meeting about The IN Group and how many of our members had benefited from the intravenous injection of gam-maglobulin. At the end of my talk a number made donations to The IN Group, totalling \$49.

I was also encouraged by Mr Wood telling me in a subsequent talk in his office that CSL would be prepared to consider funding any project that The IN Group may propose of benefit to the community. Mr Wood also suggested that The IN Group should consider setting up, in conjunction with other allied state groups, a national body based in Canberra. Such a body would be particularly helpful in lobbying the Federal Government to help in such causes as overcoming the shortage of Intragam.

Subsequently I have sent an official letter to the Federal Minister of Health the Hon Dr Carmen Lawrence, requesting her to take measures to overcome this shortage. A copy was sent to Dr Richard Kimber, Chairman, National Blood Transfusion Committee, Australian Red Cross.

Incidence GB S/'CIDF'

When investigating the patient/support group linkage I found that the Victorian Department of health records the morbidity of patients in Victorian hospitals. Morbidity is the occurrence of a medical condition and is recorded when a patient leaves hospital. If we have the total morbidity numbers for a particular disease for the year then we have its incidence.

I have now officially asked the Health Department if it could supply the morbidity figures for GBS and CIDP for Victoria for the past five years (longer if not too difficult).

Dear James,

Just a short letter to thank you and your members for their great support for our "Bingo Bear" Raffle.

Nett proceeds from the Raffle were \$380. A great effort. I'm sure you would agree.

A big thankyou however must go to my wife, Cheree. For without her untiring efforts we would not have achieved our goals.

Our Group is now a financial member of the GBS International Foundation.

Next steps are incorporation and to continue our study of GBS in Tasmania.

John Stanley

GBS Support Group of Tasmania

Thanks, John and our good wishes.

Thanks must also go to Cindy Shaw,

who raised \$32 at her Department of Social Security for the raffle and also to our member David Ashton. David won the raffle but has generously returned the Bingo Bear prize. We shall put Bingo Bear away until the next opportunity arises for a raffle.

James Gerrand

ISText:

Tuesday 9th May 3pm 4 Alandale Ave Baiwyn Dr ANDREW KORNBERG, Royal Children's Hospital, will talk on "Recent Research into Inflammatory Neuropathies". Andrew has recently returned after spending five years researching in the USA.

I look forward to seeing you there.
For details see inseri.

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GOOD HEALTH

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crawled back to the kitchen, found a pack of Mum's sleeping pills and swallowed the lot. I returned to bed hoping never to wake up.

Next morning Mum noticed the empty bottle of pills. When she came to wake me up she said, 'She'll sleep it off' he said. But Mum insisted I go to hospital.

There I was kept under observation. But it wasn't until I collapsed while out for a stroll that the doctors realised I had something more serious than flu. After that I had several tests and the next day the doctor explained: 'You have a rare viral illness called Guillain-Barre Syndrome (GBS). It's a bit like multiple sclerosis.'

but I tire easily and I'm weaker than I was before,

I was lucky. Many people with GBS are weak for years. It affects about one in 100,000 every year when a simple viral illness makes the immune system attack the covering of nerves.

My family and friends were

My family and friends were; wonderfully supportive. Without them, I wouldn't be here today.

GBS has also changed my attitude. I have much more sympathy with people with disabilities or illnesses now.

for more information contact Heather Trerranfen. GBS Support Group Inc. *Neurological Resource Centre, 37 Woomooloo Road,*

I was told I had to have a

Nothing. Woomooloo, 5A SOU. Tel: (08)2636222.

plasma exchange and was flown to Queen Elizabeth Hospital, Adelaide, that day.

First I was put in intensive care, hooked up to monitors

bladder. They gave me painkillers but nothing eased the dreadful pain deep in my bones.

Then I started the plasma exchange. A little of my blood was drained at a time and the infected plasma was separated and replaced with new, uninfected plasma. This went on regularly for two weeks. Soon my movement and feeling started coming back.

I started physiotherapy and three weeks later was moved back to Bern Hospital. I stayed there for a fortnight and was off work for two months. I'm 33 now, and feel pretty well.