

# 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).

## How the Disabled can be Socially Helped

**CINDY SHAW**

*Social Worker, Department of Social Security*

The **Mobility Allowance** is paid to people who need a lot of help to get on and off public transport. This applies anywhere in Australia. It helps to defray the cost of travel.

You need to be doing some paid work, voluntary work or training, for at least 8 hours per week to qualify.

Paid work means gainful employment and includes the following; salaried employment; carrying on a profession, trade or business; sheltered employment; self or home-based employment intended to produce financial gain. Gainful employment must always have a monetary advantage to the person so employed.

Voluntary work is for work for a recognised charitable or welfare organisation, such as the Salvation Army, St Vincent de Paul, Meals on Wheels. Working in your school tuckshop for 8 hours a week would be OK.

Working at home for parents or friends, unfortunately, does not qualify. Voluntary work must be angled at providing some service to the community at large. Work for The IN Group would qualify.

The other area is training, doing a course. Vocational training is defined as training which is aimed at providing or improving work skills, necessary for participation in the work force. It is not necessary that a person has a job to start in, after the completion of the training.

The **Mobility Allowance** is not means tested. So you can receive it in addition to any other income, including other Social Security payments.

Another feature is that there is available a six months' lump sum advance payment. This is to help you make a capital purchase, such as a motor vehicle. The lump sum, amounting to the princely sum of about \$650, can only be paid once per year.

How to apply for the **Mobility Allowance**? Your doctor would have to complete a medical report form, available from the Department of Social Security (DSS). The whole assessment is done on this report. There are certain levels of difficulty or discomfort when taking public transport that need to be gone into. There is a DSS pamphlet explaining the requirements in detail.

James was saying many members have never heard of the **Mobility Allowance** and we may know someone who is desperate for this type of payment.

When you are applying, your doctor will be assessing you on the different skills, for instance your capacity to cope with walking for 400 metres, for sitting in a bus or tram, for standing in a moving bus or train etc, crossing streets and negotiating kerbs, negotiating steps in and out of a bus or tram.

**Mobility Allowance** is paid into a bank account every second thursday. At present it is \$51.50 per fortnight. This is not very much but it is a help if you are having to take taxis instead of public transport.

You have to tell the DSS within 14 days of any significant change in your circumstances - Notifiable Events. This is because eligibility is reviewed every year. If you change your job, or your medical condition changes, or if you

stop *the* training course, then DSS needs to know to reassess the allowance. The allowance does not get immediately cut off - you get a further six weeks of allowance.

Eligibility for Mobility Allowance also makes you eligible for a Health Care Card. This provides for medical prescriptions costing only \$2.60 at your chemist and also a discount on your winter gas, electricity and water usage bills. It also provides for free ambulance, dental and eye treatment, the latter at the Royal Dental and the Royal Eye and Ear Hospitals. The problem is the long queues at these hospitals.

When applying for the Mobility Allowance you need to provide DSS with the usual proofs of identity - driver's licence, motor vehicle registration, original of birth certificate.

Another provision that could be of interest is the Carer Pension. It is paid to people who are looking after someone, either in their own home or in one that is close by. It does not have to be a partner or a relative. It is means tested, including one's partner. But many people don't realise they could be eligible for this pension, for they are looking after a loved one and are reluctant to claim because they feel it is almost a duty.

The conditions for the Carer Pension are that you must be an Australian citizen or allowed to live here permanently, you must live with or very close to the person you are caring for, and you must be providing full-time care, including the provision of such things as bathing, dressing, hygiene, eating and mobility.

The person cared for has to be over 16, and need full time care because of a severe physical, intellectual or psychiatric disability. They may need constant supervision if they are a danger to themselves or others. They need this care for more than six months. You can have a break for up to 42 days each year - respite care. You can have a part-time job, if not more than 10 hours per week.

You can have assets up to \$115,000 not including your house, with the pension cutting off at \$223,000. The Carer Pension for a single person is \$318 per fortnight and for a couple \$265 each per fortnight.

There is also Sickness Allowance and

Disability Support. But firstly I should mention the importance of privacy. You can't just walk up to a person and say, "Have you got GBS and how much money have you got in the bank and do you need help?" It is a sensitive issue. All you can say is "I am here if you want me." Even this can be difficult if the person is very sick and can't think to ask for help.

For Sickness Allowance you need to have a short term incapacity. For instance if you had GBS and were in hospital, you have a medical certificate from your doctor which said you were going to be sick for 3/6/9 months, you would be entitled to this Allowance.

If it is long term, anything more than two years, and an incapacity more than 20% plus a continuing inability to work full-time (more than 30 hours per week) then you could be eligible for Disability Support Pension. A full medical report is required.

Some people get very concerned when advised that a Commonwealth Medical Officer (CMO) needs to examine their case. For the Sickness Allowance you don't normally need to see the CMO except after 40 weeks because this allowance only goes for one year.

For the Disability Support Pension the chances are that you will see a CMO who will assess the percentage incapacity. Often a CMO won't do medical on you but will take the medical report of your own doctor and the medical forms you have filled out for DSS. The Sickness Allowance is reviewed every 3 months, the Disability Support Pension every 2 years (for some cases every 5 years).

You should make your claim within weeks of becoming ill. If made after weeks payment is not back-dated. Many people go without any income for a period when stuck in hospital and too sick to help themselves and haven't claimed. However if you are unconscious, in a coma, such that you can't ask someone to help you then, if this is the sole and dominant reason, the payment can be back-dated.

*Cindy Shaw left numbers of the various DSS pamphlets and are available to any member interested by contacting The i Group, 138 B Princess St KEW 3101 t 853 6443.*

## 11ST CONTACT

### At the Alfred

Dear James,

*After hearing of your call on 8/9/94 I was very pleased to be able to visit Philip Mortlock, a GBS patient in Ward 1A (Intensive Care) of the Alfred Hospital on the following day.*

*Philip, a farmer from near Bendigo, was in good spirits and had been in the Alfred for 7 days. We discussed the onset and recovery from GBS and the very good recovery I am making. While I was there Philip was transferred from Intensive Care to a ward so he is on the improve.*

*I found it most rewarding to be able to give a GBS sufferer similar support to what I received.*

*Philip was most appreciative of an "IN Group" member being able to have a good chat with him.*

Bryan Luscombe

Thanks for your ready support, Bryan.

### North East Victoria

Our Secretary, Vilma Clarke (Wanga-ratta), reports that this little section of Jill Grimmond (Wodonga), Lurlene Butler (Lavington NSW) and herself had a good social gathering where Vilma passed on relevant information and literature on Mobility Allowance and the like provided by Cindy Shaw, our June meeting speaker (reported this issue).

### Study

An initial group of 23 volunteers have now been interviewed and the questionnaire slightly revised. Interviews of all other volunteer members will now be carried, with the workload being shared by the three interviewees - Betty Gerrand, Graham Blanck and James Gerrand. A final part of the study may require our selecting a control group of non sufferers of GBS and CIDP.

It was interesting that the this initial trial group of 23 had 10 CIDPs - 6 diagnosed as progressive and 4 as relapsing - compared with 13 GBSs. None had any family history of inflammatory neuropathies. Of possible causes 11 of the GBSs attributed it to antecedent flu and one to surgery, whilst 2 of the CIDPs thought it might be stress, 1 from flu and 7 had no idea.

Our consultant neurologist, Dr Bruce Day, will be contacting later in the year those volunteers to this project to investigate how Intragam can be so effective for some in restoring muscle strength in some patients.

### Bin so Bear Raffle

Mr Ted Basarke, partner of member Barbara Burzak-Stefanowski, has kindly donated a beautiful Talking Bingo Bear, value \$100, as the prize for a raffle to be drawn at our Sunday 13 November midday Social Get-Together. You will receive a book of 10 \$1 tickets with this issue. Please return the butts and any unsold tickets before the 13th. Proceeds will help our IN Group endeavours and delight the lucky winner.

### LETTERS

Dear Mr Gerrand,

*I may well be your oldest member. I was 81 when struck down by GBS. Legs paralysed and hands all pins and needle - a sudden onset.*

*Good nursing and intensive physio at Grace McKellar Centre, has seen me able to walk again and fit to go home.*

*I would be happy to visit any victim from Queenscliff or Point Lonsdale.*

Mrs L M Marcard

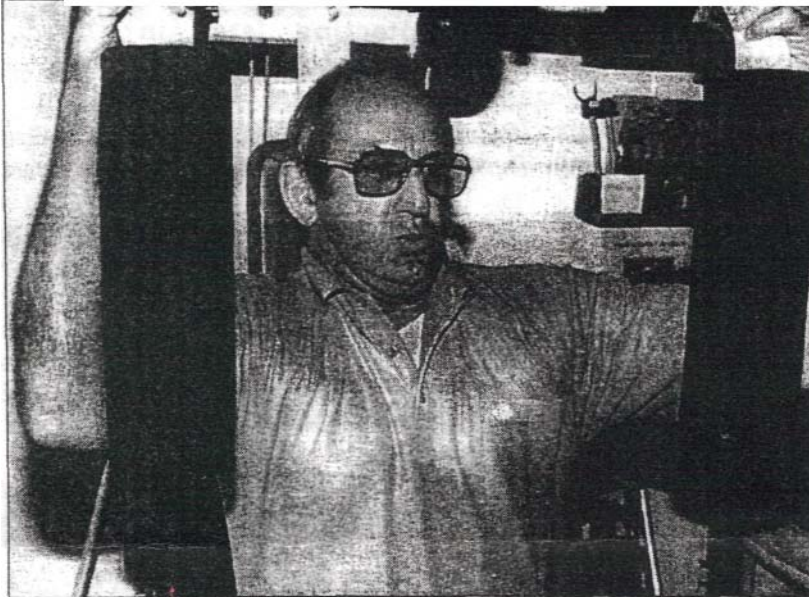
From a letter from Eileen Evers (UK) to Vilma Clarke.

(Following the reprint of Mrs Evers' article in our June'94 issue, Vilma wrote to her. These are extracts from her reply.)

*I have been given an awful lot of Intragam because things got worse again if I didn't. BUT the good news is that the time interval between hospital visits is definitely increasing and strength and feeling are nearly back to normal. So in general I feel that the "illness" is gradually receding. Anyway, whatever the future brings, it is wonderful to be able to look after my family and do things again. I feel like the Sleeping Beauty who has woken up after 5 years! Last week I played a full 18 holes of golf - not bad for someone who was told 18 months ago that I probably would never walk again!*

Mrs Eileen Evers  
Surrey, England

## Out of wheelchair and powering to recovery after rare illness



Well on the way to a full recovery, Mr Rewie Ellis is slowly rebuilding the muscles he lost to the rare and mysterious Guillain-Barre Syndrome he contracted last year.

# Rewie takes giant step to recovery

By SARAH WASHINGTON

WEDNESDAY was a big day in the life of Mildura resident Rewie Ellis.

Rewie said the bizarre thing was that he felt no physical difference. "I feel as fit today as what I did before I had this," Rewie said. The disease, which knows no age barriers and can effect anyone, has many different variations and recovery is possible.

"Some people like me have paralysis at different points, but

mine was rare in that I had complete paralysis which stopped at my knees and elbows," he said.

"It usually begins with a virus and the antibodies in your body attack that virus. "Then for some

reason they decide not to attacking the monolothium sheath in your nervous system, the one which carries the impulses from your brain to your muscles. There are some

people who have had it and I don't know how many have

gotten out of it was massive pins and needles in the hands and feet." Rewie said.

He said the illness had a major impact on his life and to rehabilitate his body, he must rebuild it from scratch using physiotherapy, weight-lifting and swimming.

"I will hopefully have full movement restored," he said.

For Rewie it is now a matter of rebuilding the muscle he lost to the illness.

He is confident he will have full recovery, with the assistance of his wife, Betty and daughter, Sue.

"I am making wonderful progress," he said.

Rewie is one of about 140 members of the Guillain-Barre Support Group in Victoria — other groups exists in New South Wales, Tasmania and South Australia.

He is the contact person for Sunraysia and anyone wanting more information can call 23 0674 or write to 226 Deakin Avenue, Mildura.

### LETTER

Dear James,

Rewie was interviewed for our local paper the other day (see above Ed) so am sending the page. Two other people phoned who have had the dreaded complaint - a girl when she was 2 and a man when 38. The man lives at Somerville and the girl, who is now 11, lived in Adelaide when she was afflicted and now lives in Mildura.

I have forwarded details of The IN Group to both so hope they both join - I'm sure it would be of interest to them.

The girl has is almost fully recovered though has weak arms. The man has been left with a shuffling walk but has his own business so is going well also.

Rewie is now walking most places on one crutch.

BETTY ELLIS  
Mildura

## SOCIAL GET-TOGETHER LUNCHEON PARTY

Sunday 13th November at 12 noon. 4 Avenue, Balwyn

This social gathering will be the opportunity members to meet at least once a year. Winter and it will be a nice sunny day.

It will be held as usual at the home of our Director, Ray Dahlitz. Thank you, Ray and

As agreed at our last meeting, we are for a luncheon, Betty and Vilma are catering,

It was the day he handed back his wheelchair, a major step on his steady path to recovery from the rare viral illness Guillain-Barre syndrome.

Rewie, 62, was struck down last year by the mystery illness, which effects the nervous system of four people in 100,000. One Sunday morning last October he got out of bed to find had lost all movement in his arms and legs.

Fortunately Rewie said his doctor had recognised the symptoms, he said. "The doctor looked in his little bag, got out his hammer and tried my testes and told me I had 1GB.

Alandale

for all will be over

Deputy Ros. charging \$10 with the

profits to The IN Group. Please come and bring any family and friends.  
I look forward to seeing you on the 13th.

JAMES GERRAND, Director

RSVP 6th November tel 853 6443