

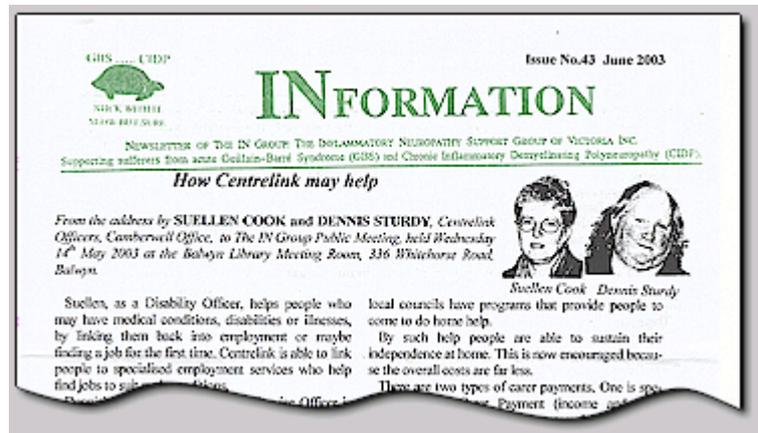
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Newsletter No.43 - June 2003

See also: [Nursing The GBS/CIDP Patient - Talk by Nurse Sue Vanselow, 13th August 2003](#)

How Centrelink may help

From the address by SUELLEN COOK and DENNIS STURDY, Centrelink Officers, Camberwell Office, to The IN Group Public Meeting, held Wednesday 14th May 2003 at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn.



SuelLEN, as a Disability Officer, helps people who may have medical conditions, disabilities or illnesses, by linking them back into employment or maybe finding a job for the first time. Centrelink is able to link people to specialised employment services who help find jobs to suit such conditions.

Dennis' main role as a Customer Service Officer is in helping people go through all the legislation to see whether people are eligible for different types of payment in relation to their circumstances. Centrelink has different types of payment that may assist people according to whether a person has a short term or a long term medical condition.

One of the main payments is the Disability Support Pension for people who have long term medical conditions or disabilities or illnesses that stop a person from being able to work full time, considered 30 hours per week. This is any work he/she may possibly do or be retrained to do in a two year period. The current single basic rate is \$440.30 per fortnight and for a couple \$367 each per fortnight. These are income and asset tested. For a couple there is also the possibility of a Carer's payment

Q. What about a person who has trouble looking after him/herself?

A. Is this a person who is able to do clerical work but can't do certain things about the house, can't clean or can't cook? If there is a friend or relative coming in at the expense of doing work they may be entitled to a Carer's payment (income and asset tested). We do allow a full time carer approximately 20 hours per week time away, possibly studying. The assessment is based on two reports on the level of care with regard to certain functions involving daily living, one by the treating health professional and one by the carer.

There are carer organisations that have paid people to come and help people. These paid carers are not paid by Centrelink but by the organisations. Often local councils have programs that provide people to come to do home help.

By such help people are able to sustain their independence at home. This is now encouraged because the overall costs are far less.

There are two types of carer payments. One is specifically called Carer Payment (income and asset

tested) which is paid on pension rates; the carer has to provide significant care on a daily basis. The other is the Carer Allowance (not income and asset tested) where the carer has to be living at the same address, a partner or perhaps a relative or friend. The treating health professional has to assess it as a medical condition which is going to last at least twelve months.

For people who have temporary conditions Centrelink has other payments. For people who are employed but have to take time off work because they are unwell there is Sickness Allowance. For people who don't have a job and are looking for work but become unwell Centrelink is able to accept medical certificates to cover them from having to look for work while they are unwell.

For people who are retired we have the Age Pension (income and asset tested). For a person looking after an aged partner they are able to access the Carer Allowance or Carer Payment.

Mobility Allowance may be available for people doing voluntary work, paid work, looking for work at a registered employment service, for at least 8 hours per week. It is granted if you are having difficulty with catching public transport by yourself. It is to help cover the cost of going to voluntary or paid work such as by your car. It is not income or asset tested. It is not necessary that you are on any other payment from Centrelink. It is \$66.20 per fortnight and includes the Health Care Card.

Through the Victorian Taxi Directorate people with difficulty catching public transport can get a card that gets you half-price for taxis. To apply you need to get a form from the Directorate that needs to be completed by your doctor to state what the medical conditions are and what difficulties you have with mobility.

For people who might be thinking about study and may be in receipt of a pension from Centrelink and want to go back and maybe retrain, possibly do another course at Tafe or university, we have a payment, the Pensioner Education Supplement. It is paid on top of the Disability Pension. There is an entry payment attached to the payment of \$62.40 per fortnight. It is not income or asset tested. You only need to be doing 25% of a full-time workload of an Austudy approved course if in receipt of Disability Supplement.

There are some employment services that may assist people in going back to work. They are free and one does not have to be on any payment from Centrelink to access. The types of services range include assisting a person to figure out a new career they may want to do and how to manage their medical condition in doing so. If people have been doing a physical type of work they can help a person to retrain into say a sedentary, desk job clerical work. For people who may need help in learning, managing new jobs, sometimes some of the employment services can provide people to go with that person to the job and make sure they know what they are doing.

Another component of the employment services is to help people adjust to the work place. There is funding to help set up a person in a work site with appropriate equipment if adjustments need to be made to benches, computers, seating arrangements etc. There are work place assessors that can go with that person.

The program, Job in Jeopardy, is funded and run through CRS Australia which is Centrelink's Vocational Rehabilitation Service provider. Their people are trained occupational therapists and physiotherapists who are experts in the field of assisting people with medical conditions with going back to work. If you have a job and your medical condition is impacting on the way you doing things such that your employers are getting concerned then you can contact these services and see if you can get them to come out to assist you to adjust to your work place. People with poor eyesight can get screens that magnify the computer display. People who are blind can get equipment that enables one to talk to the computer which will then type for you.

There are several types of Concession Cards. There is the Pension Concession Card and the Health

Care Card which reduce costs in public transport, winter gas and electricity bills, car registration and pharmaceuticals and provide a phone allowance.

Centrelink has Financial Information Officers, a free service, who can advise people on how best to handle their income and assets with respect to Centrelink

The Commonwealth Seniors Health Card is for people who don't qualify for a pension. It is based on taxable income; if you have an annual adjusted income of less than \$50,000 for a single person or less than \$80,000 for a couple, and over Age Pension age you are eligible for the Card which gives you cheaper pharmaceuticals.

The Pensioner Bonus Scheme is for people who are Age Pension age but want to defer the Pension because they are still working. You need to register for the Scheme through Centrelink. You can defer for a maximum of 5 years and then receive the Bonus on the basis that during that period you were not receiving the pension. You must have paid work for at least 960 hours per year for the Bonus. You cannot accrue Bonus over 75 years old. It is a tax free bonus. Both members of a couple should register if of age pension age continuing to work for at least one year are likely to receive some pension when they claim.

A person on a Disability Support Pension is asked when they reach Age Pension age if they want to change to Age Pension. Some people don't not-withstanding that the Disability Pension becomes taxable because they perceive certain benefits from recognised as a person with a disability.

The age for males to receive the Age Pension is 65 and for females, presently 62.5 ? it moves forward half a year every year and a half, eventually ending at 65. A difficulty is knowing how long a medical condition can last. For example one may recover from GBS in a few months or it may last for a year or many more. Centrelink has to rely on medical expert advice. It has a Disability Officer in every office to advise advice to the staff and the public.

Suellen brought copies of the many Centrelink publications, detailing the wide variety of help their service provides, which many at the meeting were able to take away. In particular The IN Group has now available for reference to members the Centrelink "Bible" ? their "Centrelink Information" a 205 page guide to payments and services 2002-2003.

The IN Group News

Cake Stall Success

Our now annual Cake Stall held at Maling Road Canterbury on Saturday morning 10th May was another fine success. A total of \$707 (including monetary donations of \$95) was raised from the many cakes, biscuits, jams, quinces, passion fruit and pumpkins donated by many of our members.

Our thanks to the five who manned the stall and made many cakes ? **MARGARET LAWRENCE** (the initiator and main organiser of this fundraising feature), **BETTY GERRAND, BARBARA RIV-ETT, DOROTHY BRENNAN** and **BARBARA CLIFFORD** - as well as to the many other contrib-utors who included **BRONWYN CLARKE, ROSE-MARY MacQUALTER, RAE MALCOLM** and **LUCY TIDBURY**. A leaflet about The IN Group was appreciated by customers.

Winter Social Luncheon

Margaret Lawrence will again be our hostess for The In Group **Winter Social Luncheon** to be

held from noon on Sunday 22nd June at her home 26 Belmont Street, Glen Waverley. \$15 will provide a lovely luncheon as well as raising funds for medical research. **Vilma Clarke** has arranged for a friend and her daughter to provide a pleasing musical interlude.

VCJD Donor Deferral Workshop

Director **JAMES GERRAND** "showed The IN Group flag" at this meeting held 28th February of high level Commonwealth and Victorian Government, Australian Red Cross Blood Service, CSL and blood recipient officials to discuss the impact of the Variant Creutzfeldt-Jacob ("mad cow") Disease. Presently people who have stayed in the UK for more than 6 months in recent years are not allowed to donate blood in Australia. This ban has reduced blood donations in Australia by some 5%. **JAMES** expressed The IN Group's concern about this reduction. He stated that many of our members are suffering from the 20% shortfall in the supply "Intragam" made from blood and plasma from kind donors.

Following the meeting, James Gerrand has received private welcome advice that Commonwealth and State governments may have agreed to more funding to increase the supply of blood and plasma donations such that within twelve months we can expect an increase in the supply of Intragam to meet the medical needs.

\$875 from Vic Govt

The Department of Human Services has again rewarded The IN Group for our community support by awarding us this year \$875. (Last year was \$850).

Our thanks to the Department for this recognition.

\$1,000 from CSL Bioplasma

CSL has continued their generous support of The IN Group by again contributing \$1,000 to us for the financial year 2003/2004. This payment effectively covers our costs of the Internet, such an immediate means of communicating with anybody worldwide.

GBS/CIDP Awareness Day 1st June 2003-05-19

The Council of GBS/CIDP Support Groups of Australia again set 1st June as our national Awareness Day. The IN Group issued a Media Release with the theme "**A Big Thank You to Blood and Plasma Donors**", hoping our appreciation will stir a media exposure. The Red Cross Blood Service warmly welcome this expression of gratitude. (This Release is printed on the back of our wrapper).

Member and school girl **ANNE MELVILLE** emailed The IN Group to advise that she is arranging a fundraiser at her school for The IN Group as part of our Awareness Day. Anne is Social Service Captain at her school. She suffers from CIDP and last year ran a campaign to recruit her school friends as blood donors (featured in "INformation" Sep 2002).

ANNE, thanks for your great and continuing support!

Film Luncheons

Eighteen members and friends thoroughly enjoyed "Chicago" at the Balwyn Cinema on the 19th February and getting together over the lunch. that followed.

Nine members and friends saw "Anger Management" on the 13th May. Some found it entertaining but others thought it was rather over the top.

Entertainment Books

Twelve of the Greater Melbourne 2003/2004 Books that feature discount on dining, hotel accommodation, theatre, sporting and more, have already been sold. Buying a Book for \$55 (\$60 including postage) also rewards The IN Group by \$11!

Summer Blood Challenge

JAMES GERRAND on behalf of The IN Group attended the Summer Blood Challenge Awards Breakfast 2003. This annual event is arranged by the Australian Red Cross Blood Service. Our Treasurer **BRONWYN CLARKE** organises a team to donate; this year The Inflammatory Neuropathy Support Group of Victoria Inc. was on the list of challenges with 7 donors over the 3 months. The winner was the Firefighters ? CFB & MFB with 275. James was pleased to meet up with member **KYLIE MILLER**, representing the 35 donors from "The Age".

Support is the Name of our Game

Personal Support

Both **Keith Colwill** and **JAMES GERRAND** visit-ed the ex-Governor of Victoria, the Hon **RICHARD McGARVIE AC**, recovering from a severe attack of Guillain/Barré syndrome (GBS) at the Monash Medi-cal Centre. Richard was then severely paralysed in his legs and arms but has since recovered enough to be transferred for rehab at the Bethlehem Hospital. His paralysis did not deter him from being interviewed by John Faine on radio 3LO, on an evening TV program and having an article published in the Opinion page of "The Age", in support of his friend Dr Peter Hollingworth and denouncing the media attack on Peter. Richard is pleased to become a member of The IN Group.

New Members

A warm welcome to new members **Graeme Boltwood, Cherrilyn Collins (ACT), Garry Cutler, Joyce Dickson (WA), Anne Drover (NSW), Lyne Grimes, Gayle Harding (NSW), Maureen Hinds, Joan Hooper, Mick Jordan, Patricia Kenny (NSW), Greta King (NT), Alan Litchfield (NSW), Mario Lombardo, Lorraine Manson, Richard McGarvie, B.A. McLaughlin, Robyn McMahan, Carolota Miller (USA), Debbie Moors, Neil Searle, Mary Simpson, Stewart Stone, Audrey Taplin (Tas), Peter Taylor, Wilhelmas VanDijk (Qld), Curtis Vincent (USA), A.H.Walker and Margaret Wilson.**

Support through the Internet

Over the past 3 months some 25 emails were received, mainly seeking information about GBS or CIDP. These included 7 from overseas (5 USA, 1 Canada and 1 Finland) and 3 interstate (NSW, Qld and WA). A GBS or CIDP booklet plus The IN Group brochure and latest newsletter were usually posted after obtaining a postal address. One result was 6 new members; another was some complimentary remarks such as:

"Love your newsletter. Much better than any here in USA! ? Rebecca Keller, USA

"You might not get a lot of messages giving you proper credit and praise, but believe me sir, it's

much appreciated by many. Chad, USA"

"Great site. As a CIDP sufferer myself, I truly appreciate it. Calxs, USA"

"I always find reading the newsletter informative and congratulate you on the work that you do, Barry Henzell, Qld."

"Thank you very much you are greatly appreciated. Colleen Wilson, Bendigo"

Such appreciation of the support by The IN Group makes any work involved by any of its members so wonderfully worthwhile.

Some Medical Advice

Q. My wife, a long time sufferer from CIDP, has been found to have raised levels of a MAG antibody. Her specialist has recommended a course of Mabthera. Any comment? Barry Henzell.

A. As mentioned in my recent talk, MAG neuropathy is CIDP like and Ritaximab is a treatment. Dr Andrew Kornberg.

Q. Melva Behr has suggested that CIDP sufferers may have an overactive immune system. What is your comment? James Gerrand.

A. People have looked at this but there is no data to suggest it. There is no question the immune system is overactive but how and why is not known. Dr Andrew Kornberg.

Q. Spring greetings. I like to drink sometimes a little wine and little drinks. Is it unsuitable for a CIDP patient? Kari Hoti, Finland.

A. Here in Australia where alcohol is compulsory we have not been able to do any studies to see the effect of complete abstinence on CIDP. Seriously though, although alcohol can be considered toxic to nerve, it is likely that most "alcoholic neuropathy" is probably due to nutritional deficiency. So if your correspond-ent maintains a healthy diet and a modest alcohol intake I would think it is very unlikely the occasional glass of wine will be of harm. Dr Bruce Day.

Promising Nerve Regeneration Study

Dr Sanfe Sahenk, Professor of Neurology at Ohio State University, is investigating the ability of a new drug, NT-3, to protect and regenerate peripheral nerves.

"We have found that treating mice that have defective myelin sheaths with NT-3 resulted in significant regeneration of their nerve fibres". "Our group is now conducting a clinical pilot study to determine whether NT-3 can help patients with CMT."

Dr Sahenk believes that demyelinating neuropathies such as CMT, CIDP, MAG and GBS among others, have a deficiency of NT-3 resulting in breakdown of axons. They have found that normal axons surrounded by sick Schwann cells degenerate and fail to regenerate, whereas they can regenerate if surrounded by normal Schwann cells or given NT-3.

(Item supplied by Lucy & Charlie Tidbury forwarded on by Rosemary MacQualter. Thanks, Editor.)

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