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Newsletter No.46 - March 2004

Council Care for the Disabled

*From the address by **WENDY PHILLIPS**, Disability Care Officer, City of Boroondara, to The IN Group Public Meeting, held Wednesday 11th February 2004 at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn.*

See also: [Social Event 12-May-2004](#)

Home and Community Care Program

I work within the Health and Aged Services Department - predominantly in the Home and Community Care program (HACC). This program is funded jointly by the Commonwealth and the State Governments. It supplies a range of support services to allow people to remain as independent as possible in their own home. It is targeted to frail older people and people with disabilities and their carers, who live at home and whose capacity for independent living is at risk or who are at risk of premature or inappropriate admission to long term residential care.

The age of frail age has gone up over the years as people live longer. When the program started 20 years ago people used to get the services at about 60 but now we consider frail age as being more in the high 70s. The younger people with disabilities range from 0 to 64 with all sorts of disabilities.

The program provides a comprehensive, coordinated and integrated range of basic maintenance and support services. It provides flexible, timely services that respond to the needs of its customers.

HACC Target Group

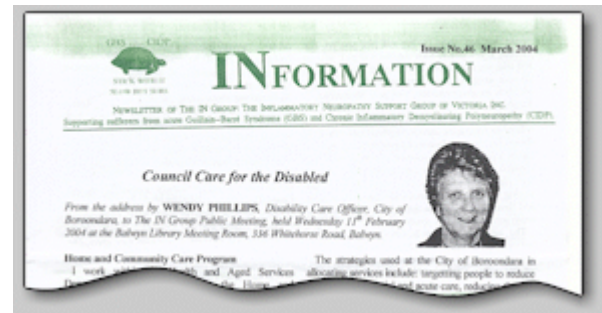
People within the target group need to be prioritised and assessed for eligibility. The target population comprises the people living in the community who in the absence of basic maintenance are at risk of premature or long term residential care.

The main target groups are the frail elderly people with moderate to severe and profound disabilities and younger persons with moderate to severe or profound disabilities.

In assessing for HACC, the tasks of daily living we look at, include assistance in the home, preparing meals, dressing, home maintenance, and personal care attendant.

The strategies used at the City of Boroondara in allocating services include: targeting people to reduce the risk of residential and acute care, reducing the risk of premature and inappropriate admission into residential services, assisting clients with high, complex needs to remain within the community, improving functioning and supporting independence within the community, supporting carers of the frail and disabled, and reducing an unmet need for the above services.

We have over 2,500 clients. The types of service we provide is firstly Home Care, which is basic cleaning of the house, (we don't clean windows, it is not a blue ribbon service), vacuuming the



house, maybe cleaning the bathroom, assisting with the shopping - those services needed for people to remain safely at home.

Then we provide Personal Care which includes assisting people to have a shower or bath. Some people may need full assistance while others may just need somebody there so they feel safe.

We provide Meals on Wheels - a hot meal delivered during the day, a three course consisting of soup, meat and veg or what you order (there is a menu) and sweet.

There is a Respite Service - somebody will come into the house to relieve for a day a Carer who has been looking after the disabled one.

We have a Social Support program and that includes the Senior Citizen Clubs. We run a couple of social functions through the year, one of them is a lunch for centenarians. We run a Christmas lunch at a restaurant for disabled who are socially isolated. We have throughout the year different sorts of lunches - we might have a Chinese lunch with entertainment for Boroondara Senior Citizens.

Community Transport is provided. We have some Community buses. In some areas of the City there is a regular bus run where the bus will pick you up. For instance if you live in Kew the bus will pick you up and take you the Kew shopping centre where you can do your shopping. It also has runs to the local library and there are also excursions such as to Sherbrooke.

Eligibility

To be eligible you have to be assessed. You put in a referral to receive the service. Anybody can submit; it doesn't have to be a doctor or a professional person, it can be a family member, yourself. The level of service required is then looked at. Somebody will visit and numerous forms will needed to be filled in. The person visiting will discuss the various services we can offer and then decide the most appropriate type and how much service.

The service we offer is not just based on a person's needs but is also based on all the other 2,500 clients we have. We have to balance up what we are offering in relation to overall needs. We have only limited resources which must be apportioned.

Ineligibility

People are not eligible for provision of accommodation, of aids and appliances, of direct treatment for acute illness. Residents of aged care facilities or recipients of disability program accommodation support service are not eligible for HACC. There are other services for these provisions or such recipients. For example PADP provides wheelchairs and other such physical support items.

Fees

All consumers, assessed as having capacity to pay, are charged fees. These are in accordance with the scale appropriate to the consumer's level of income, amount of services used and individual circumstances.

Income levels (before tax)

Low: Single - under \$23,029.50; Couple - under \$38,512.50; Family - under \$42,146.00.

Medium: Single - under \$51,524.00; Couple - under \$68,907.30; Family - under \$72,535.10.

High: Single - over \$51,524.00; Couple - over \$68,907.30; Family - over \$72,535.10.

Charges per hour

Personal Care: Low \$1.10 - \$3.30; Medium \$4.40 - \$6.60; High \$27.60.

Respite Care: Low \$1.10 - \$2.20; Medium \$2.20 - \$3.30; High \$24.64.

House Care: Low \$3.30 - \$4.40; Medium \$5.50 - \$11.00; High \$23.84.

Home maintenance (plus cost of materials): Low \$4.40 - \$8.80; Medium \$9.90 - \$13.45; High \$34.68.

Questions & Answers

Q. How about fees for the 0-64s?

A. In talking about young children that aren't on a pension, the fee is based on the family income. If you are a young person with a disability and you have a partner who works, again it is the joint income. If there is a large medical expense or other such expenses then that is subtracted from the income.

Q. Is your program totally supported by the Council?

A. No, it is a Federal and State Government initiative. I can't tell you how much money we get because I have nothing to do with that area. The Council does provide some amount but it is mainly government money.

Q. Do all the Victorian Councils provide this service?

A. The HACC program operates throughout Australia. In Victoria it operates through the councils. The HACC guidelines are the same for every council.

Q. How about young people with a disability living on their own?

A. It would be best for such a person to contact their council to see what could be provided. Ring the council number and ask for Aged Services.

Q. Do all councils have a Disability Care Officer?

A. No, we are very lucky at Boroondara. The position has been there for only two years and at the moment Boroondara is the only council that has it. We also have a Disability Access Office. We have a Community Disability Advisory Council which is a group of council officers (the Disability Access Officer and myself are on it) and community reps (most with disability) which looks at access for people with disabilities. This includes the Multi-Purpose Taxi Card. The Access Officer prepares a four year Disability Access Plan which looks at ways the council can improve access for people with disabilities.

Q. How many staff would the council have to look after the 2,500 clients?

A. Staff is a real problem, a scarce resource. We probably have about 100. It is not a huge amount

and they work very hard. They work all day. Then we ring them up and say will you go and do a Respite shift for us to night?

(Wendy Phillips left a number of Council and other caring organisation pamphlets with The In Group)

The IN Group awarded \$1,300

The Victorian Department of Human Services has awarded The IN Group \$1,300 under its Health Self Help Program 2003/2004 in recognition of our playing a "vital role" in the health care system. Last year The In Group was awarded \$875 under this same Victorian government program.

These awards are a tribute to the help you members have contributed to assisting sufferers from the inflam-matry peripheral neuropathies, mainly GBS and CIDP.

Support is the Name of our Game

Personal Visits

MIRABELLA CALUGARU, a 28 year old microbiologist recovering from GBS at the Alfred Hospital was visited by **JAN LANE** (of Sunbury who has had GBS), **JAMES GERRAND** (Director of The IN Group who was contacted by mother **CLAUDIA**) and **KAREN WEIR** (who had GBS some 7 years ago when he was 17). The patient and her parents were very appreciative of the visits and have joined The IN Group. Mirabella is now in rehabilitation at the Caulfield Hospital.

MIKE ROSTOKS, a 24 year old, studying man-agent at University and working part time, was under treatment at St Vincent's Private Hospital for Miller Fisher Syndrome, a rather rare variant of GBS, when visited by **JAMES GERRAND** who had been contacted by mother **CLARE**. Patient and mother greatly appreciated the visit.

Support Contacts

James,

*I have discovered your group on the net. My name is **PETER ROBINSON** and CIDP has been part of my life for the past 4 years. I live at Baraduda (near Wodonga) and after reading your newsletter I was surprised to find I am not alone in this area. I am keen to be involved with The IN Group.*

Peter was sent The IN Group membership application form and a welcome to the Group.

Dear James,

I am writing to thank you very much for sending the literature and info on membership of the IN Group.

My husband Stuart has CIDP which took about 10 years to diagnose and he is having plasma exchange at the Alfred Hospital once a month which makes him a lot better. WE started the plasma exchange in early 2000. His balance is still not good and he needs to watch it all the time but has lost the overwhelming tiredness that he had before treatment. He works on our property with our son cropping 900 acres and running 10,000 sheep with a very small vineyard growing shiraz and cabernet grapes. We also run a Farmstay business mainly hosting international guests wishing to

see the real country Australia. Our clients mainly come from an agency in Sydney. In fact, this is how we heard of The IN Group. One of our guests from UK had CIDP and when she returned to UK she sent information about the support groups there and so we saw your name with an address in Melbourne. Consequently we took the information to the nurses at The Alfred and of course they knew all about you but had thought we already knew about your group. As you can imagine our lives are busy with treatments that take 3 days out of every month (we drive down the day before - over 4 hours drive and drive home the day after). We are very grateful for the supportive nurses at the Hospital, they seem now to be part of our family.

Sincerely Margaret Dufty.

MARGARET and **STUART DUFTY** have joined The IN Group. A big welcome to you both.

Multifocal Motor Neuropathy

Hi James,

I was doing a bit of random surfing and entered ?Multifocal Motor Neuropathy and up popped The In Group. I'm fit and well and based in NSW. My symptoms began around 1988 so I've been living with this for awhile.

Vanessa Rowland.

Reply

Hi Vanessa,

Yes we do support MMN as a variant of GBS. The GBS booklet of the US based GBS Foundation International has a section dealing with MMN. I could post you a copy plus The IN Group brochure and latest quarterly newsletter "INformation" if you send me your address.

James Gerrand, Director.

Reply

Thanks yes, I'd be happy to join. My address is 13 Reserve St. Annandale NSW.

Cheers, Vanessa.

A Very Nice Appreciation

Dear James,

*As I looked through my back dated **INformation** newsletters for the article on Pain Management it made me realize just how much work that you have put into making our support group such a success. There were a total of 45 issues in my folder each one having been typed, collated, edited etc. This is an important part of the group as it reaches those who are unable to come to meetings and people worldwide. I am sure there are other members who also appreciate the amount of time that you and your wife Betty and also the hard working committee give to helping others overcome their illness.*

Best wishes and THANK YOU from all of us,

JUNE CATHCART, Stawell.

Reply

Dear June,

I can speak for all the Committee that it is the many grateful appreciations of what we do to help that makes our support all so worthwhile. For my own part, I can think of no better way to spend my spare time, now I'm retired, in doing what I can to help.

Many thanks, June, for your appreciation.

James.

A letter from the USA

Dear Sir or Madam,

I am writing on behalf of a CIDP patient who has been receiving infusions of PolyGam for several years now. She has recently come to learn that her insurance has a life time "cap" on medical coverage and is rapidly approaching that cap. Being that she is only 43 years old, it was no surprise to find her deeply distraught about losing her means of affording her PolyGam infusions, without which she would end up in a wheelchair. Does The IN Group offer any means of assistance ?

Paul Guillory, RN, Kapiolani Medical Center, Hawaii, USA.

Reply

Dear Paul Guillory,

I am afraid the CIDP patient is a victim of the USA medical system. Australia has a Medicare system that provides free medical treatment, as prescribed by a doctor. I was diagnosed with CIDP some 12 years ago and my medical treatment, mainly intravenous gammaglobulin every fortnight at a Melbourne hospital costs me nothing but costs my federal government about AUS\$3,000 each time.

Perhaps if the patient could travel to Australia or Canada she may get treatment for free. Otherwise I suggest you contact the GBS Foundation International (tel (610) 667-0131).

James Gerrand, Director.

Providing Information

The In Group continues to receive many requests for information about how we may help with GBS or CIDP or its variants, particularly through the Internet.

Amongst those sent material were **IVKA GRIFFIN**, Social Worker at the Royal Children's Hospital, **SANDY ELLIS** of Gilgai NSW, **GEORGIE MORTIMER**, Social Worker at the Monash Medical Centre, **SASCHA SCHUBIGER**, Occupational Therapist at the Melbourne Extended Care & Rehabilitation Service, **RACHEL WILKINS**, Information & Administration Officer of the Brain Foundation Victoria, supporting people with Acquired Brain Injury and Progressive Neurological Disorders.

Report on Patient

Dear James,

*Just a short note to let you know how **CHRIS** (sufferer from CIDP) is doing. We run a small business in South Gippsland. We had to employ our son Clint to carry out the deliveries that Chris can no longer manage. I feel I should mention again, your visit helped not only Chris but myself tremendously. To be able to speak to somebody who has been through this terrible thing showed that life was still worth living. Chris has recovered extremely well; he works on Mondays driving and delivering and goes with Clint on Thursdays and helps. Chris gets very tired easily, his eyes are very sensitive to lights and sunshine, his feet and legs aren't as strong as before, but overall we are so very lucky that he has nearly fully recovered.*

Regards, **JENNY GOOCH.**

SUMMER BLOOD CHALLENGE

The 2003/04 Results as at 09/01/04 showed the IN Group ranked 30 out of 46 ranked organisations with 8 donors. It seems that our special newsletter to encourage more donors was not successful. However it was worth a trial. Thanks to **BRONWYN CLARKE** for again organising The In Group participation.

Doubt re Roosevelt's polio

Franklin D. Roosevelt's triumph over disability, his ascent to the USA presidency, his reputation as one of the greatest Americans of the 20th century - all are inextricably linked to the disease that paralysed his legs in 1921, when he was 39 years old. That disease, everyone knows, was polio.

Now a group of doctors are calling the diagnosis into question. In the *Journal of Medical Biography*, the researchers say that FDR probably had GBS. Much of the thesis hangs on the argument that, as a 39 year old man, Roosevelt was very unlikely to get polio.

Before the advent of a vaccine in the 1950s, most victims were infected in infancy or childhood.

Books, Videos Overdue or Outstanding

There are a few books and videos that have been borrowed and are now overdue or outstanding . If you have one would you return it Barbara Rivett, 66 Eva Street CLAYTON 3168 tel 9543 2825 or to James Gerrand, 138B Princess St Kew 3101 tel 9853 6443.

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