

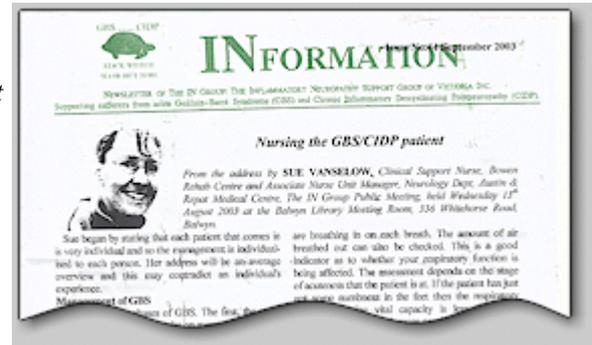
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Newsletter No.44 - September 2003

Nursing the GBS/CIDP Patient

From the address by SUE VANSELOW, Clinical Support Nurse, Bowen Rehab Centre and Associate Nurse Unit Manager, Neurology Dept, Austin & Repat Medical Centre, The IN Group Public Meeting, held Wednesday 13th August 2003 at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn.

Sue began by stating that each patient that comes in is very individual and so the management is individualised to each person. Her address will be an average overview and this may contradict an individual's experience.



Management of GBS

There are three phases of GBS. The first, the acute phase, lasts one to two weeks on average where there is a worsening of the condition.

The second is the plateau phase where there is no change in the symptoms. This can be a few days or can last up to a few weeks.

The third is the rehabilitation phase and is usually months - four months at least - and may go on for years.

The nursing management depends on which phase the patient is at. It works very closely with the medical management. Nurses are very much involved administering such medical treatments as Intragam or preparing a patient for plasmapheresis.

A big part of the nursing role is assessment. What nursing management is needed depends on which nerves have been affected and to what extent. The most important aspect of concern is respiratory assessment. If the respiratory muscles are involved then the patient can be in real trouble in breathing. We look at respiratory rate and how well the patient is breathing.

We also look to see if patients are trying to use muscles, such as in the stomach and the neck, extra to the normal muscles used in breathing. If you have difficulty in breathing these are the extra muscles you will start using as well.

So just as your nurse is going by, you have no idea that they are looking at you, checking "how well are they breathing" in a mental assessment.

The other thing assessed quite regularly is "vital capacity". This is looking at the amount of air that you are breathing in on each breath. The amount of air breathed out can also be checked. This is a good indicator as to whether your respiratory function is being affected. The assessment depends on the stage of acuteness that the patient is at. If the patient has just got some numbness in the feet then the respiratory assessment using vital capacity is less than with patients who have much more

paralysis. Some of you here may have been woken up at 2am to blow into the machine.

If we think the patient's respiratory function is going down then a blood test may be required to check the amount of oxygen being exchanged into the blood.

Other things we assess are weakness, swallowing (occasionally affected), the autonomic system - which controls the heart rate and blood pressure. Sometimes patients have to be hooked up to cardiac monitors.

Once the assessment has been made, we look at supporting the symptoms the patient may have. The medical treatment aims to slow down the progress of the disease and accelerate the arrival of the plateau stage. For example, support can be provided with ambulation, eg walking sticks or a frame, to a patient with leg weakness. They may need assistance to turn in bed. Bed-bound patients may require compression stockings to prevent getting blood clots in the leg. Patients may be provided with pressure mattresses to provide passive movements. If a patient has little or no arm movement then they will need help in eating, showering, dressing.

Patients with respiratory problem may need to end up in Intensive Care on ventilation for some period of time. Setting patients up in bed can help respiration by expanding the lungs. Some patients may need oxygen therapy to help their breathing. With swallowing difficulty a patient may need to go on a modified diet - foods easier to chew and swallow. Sometimes a patient may need to stop eating because of eating not being safe, the food may go into their lungs, so a tube is inserted to convey the nutrition.

Communication may become a problem, particularly if a patient is very paralysed or has a tube in his mouth. Other ways to communicate are then looked at such as pictures to point to, written communication.

Psychological support is a big part of the nursing role. When a patient is afflicted it can be very scary for them. Many have never heard of the disease or don't understand what to expect. So psychological support and education to inform about the disease process is very important.

Pain management is also important. 25% of sufferers experience pain. Pain is more common in the recovery phase than in the acute phase. It is pretty distressing to a patient to be told "You are getting better and that's why you are experiencing pain." The most common drugs used for pain management are morphine, paphentonal and gammaphentonal.

Bowel and bladder care are also important. Diet regimes and medication need to be started at times, or catheters need to be put in. Patients with high or low blood pressure need to be given the prescribed medications.

Sleep dysfunction is a really big problem. Hospitals are a noisy environment, lights are often on, you don't get good sleep. Part of recovery is rest. Nurses keep disturbances to the patient to a minimum.

Stress ulcers in the stomach can occur in GBS patients. It is important to keep nutrition up as food in the stomach helps avoid stress ulcers as does psychological support. Sometimes medication is needed.

Rehabilitation phase

Then there is the plateau phase and the rehabilitation phase where the remyelination occurs, a very slow process. It can be as an inpatient or an outpatient, depending on the person and condition. The main areas concentrated on during this phase are arm strength, leg strength and swallowing.

Some people after rehabilitation may be left with some residual weakness or deficit. 80% make a complete recovery.

CIDP

Whilst there is about a 5% deathrate in GBS due to associated ailments, the deathrate for CIDP is negligible. The illness is much longer than for GBS and usually the respiratory muscles are not affected.

The nursing aims for CIDP are the same as for GBS; to assess and control the symptoms, to improve function, help with rehabilitation and look for long term remission.

It is important for patients with CIDP to keep active, to keep the muscles you have got at optimal strength without overdoing it, have good nutrition and keep weight within normal healthy range.

The ward at the Austin where Sue works has designated rest periods - in the morning, in the middle of the day and later in the evening. During this time the staff try to do as little as possible. This has been found to help patients recuperate.

Q. Are patients given information about their GBS or CIDP by the hospital staff?

A. There is a lot done to explain, to the patient but also their family, what to expect. At the same time it is explained that this is the average course..

Q. Is there support given to emotional upset caused by GBS or CIDP - anger, sorrow, hurt?

A. Each patient is taken individually. We do try to place a patient in a peaceful environment as soon as treatment is complete, such as connection to monitors, respiratory assessments done half-hourly, hourly for some days. The treatment may have to be carried out in a busy environment of other patients being treated.

Trial treatment for CIDP

Thank you for giving me the opportunity of notifying your members about a new trial in CIDP, for which the Royal Melbourne Hospital, as well as a few other Australian centres, have been chosen as investigator sites. This is a double-blind, placebo-controlled study using AVONEX (Interferon Beta-1a) in subjects already receiving a stable regimen of intravenous immunoglobulin (either 2 or 4 weekly). Patients must have had CIDP for at least 6 months, be on a stable dose of IVIg for at least 3 months and must **not** be receiving other immuno-suppressive agents such as prednisolone, Imuran or cyclosporine. The study will involve once or twice weekly injections of AVONEX. This agent has been used successfully in patients with multiple sclerosis, but this is the first trial in CIDP.

I would be very pleased if any eligible and interested patients could contact me about participation in the trial. Patients could contact my trial coordinator, Dr. Lachlan Macgregor on pager 93871000, or myself on 93471550. I would be pleased to present the details of the trial at one of your meetings when further details become available.

Dr. Lyn Kiers, Department of Neurology & Clinical Neurophysiology, Royal Melbourne Hospital,
Royal Parade, Parkville. 3050

DIRECTOR'S REPORT Year 2001/2002

Continued shortage of Intragam

The shortage of Intragam has continued with many patients still receiving only 80% of prescribed amount.

Four of our members were outstanding in promoting the need for more blood donors. **ANNE MELVILLE** with some 40 of her Gippsland Grammar School fellow pupils were featured in the "Sunday Age" 28/7/03. Her friends, aware of Anne's need for blood product "Intragam" treatment for her CIDP, had all offered to donate blood. **KYLIE MILLER** featured in an article (28/08/02 "The Age") to highlight the importance of blood donations. **BARBARA PHILIPPI** had a letter in the "Warragul Gazette" (21/08/03) thanking blood donors who were so important for treatment of her CIDP. Our Treasurer **BRONWYN CLARKE** again organised an IN Group entry into the Red Cross Summer Blood Challenge.

The **GBS/CIDP Awareness Day** media release featured "**A Big Thank You to Blood and Plasma Donors**."

VCJD Donor Deferral Workshop

Director **JAMES GERRAND** represented The IN Group at this "mad cow" disease workshop (28/02/03) of high level officials from the Commonwealth and Victorian Governments, Australian Red Cross Blood Service, CSL and blood recipient organisations. Presently people who have stayed in the UK for more than six months in recent years are not allowed to donate blood in Australia. This has reduced blood donations in Australia by some 5%. **JAMES** expressed The IN Group's concern about this reduction.

Opening of new CSL Laboratory

The CSL Nucleic Acid Testing Amplification Laboratory, at Broadmeadows, costing \$10 million, was opened by the Victorian Treasurer John Brumby 1/10/02. This laboratory reduces the incubation period for blood donations from 60 days to 20 days, improving the safety of their gammaglobulin product, already a world leader in safety.

Personal Support

The IN Group has continued its main purpose of providing personal support to GBS and CIDP sufferers and their families and friends. Visits were made by **KEITH COLWILL**, **JAMES GERRAND** and **PAULLINE WHITELOW** to patients and contacts made to their families at the Monash Medical St Vincent's Hospital and the Royal Melbourne Hospital, Centre, Box Hill Hospital, Brighton Rehab Centre, Hampton Rehabilitation Hospital, Monash Medical Centre.

VILMA CLARKE continued to arrange helpful meetings of our members in the North East Victoria area, with membership now 12 coming from Cooma, Wangaratta, Wooragee, Wodonga, Albury, Myrhee.

Such help has been backed up by the continuing support of our Patrons, Consultants, Committee, members, family and friends.

Internet Support

The IN Group continues to provide support worldwide through being on the Internet. We received

about 100 email messages during the year from sufferers from GBS and CIDP seeking information about the rare disorder. We usually airmail back the appropriate GBS or CIDP booklet and latest news-letter "INformation". This response is greatly appreciated and many subsequently join The IN Group.

Sponsorship by CSL LIMITED

The IN Group is most grateful for the continuing financial support of CSL (makers of the gamma-globulin product Intragam). This support has covered the cost of being on the Internet since 1955, by their initial donation of \$3,500 for a computer/-printer, a further donation of \$6,000 in 2000 for a photocopier and annual donations of \$1,000.

ANZ Bank's Support

The ANZ has continued its helpful support of The In Group by not charging their fee (\$15) for changing foreign currency, usually overseas subscriptions and donations.

Membership

Membership is 288 which includes some 220 past and present IN sufferers. Thanks mostly to being on the Internet, 38 are from interstate and 32 from overseas - mainly from the USA but also from Canada, New Zealand, and the UK.

I particularly thank the many members who donated generously to our cause. The \$10 annual subscription covers our running costs such as the newsletter "INformation". The donations, a wonderful \$2909 from members, allow us to expand our efforts, particularly in helping the research into GBS and CIDP being carried out by Dr **ANDREW KORNBERG** at the Royal Children's and St Vincent's Hospitals. We donated another \$7,500 to this research, making a total of \$43,500 to date.

Quarterly Meetings

These meetings have continued to be popular. Quality speakers for the evening meetings ? Dr **GRACE WARREN**, Orthopaedic Surgeon on "*Reducing the Disabilities in Polyneuropathy*" August'02; Dr **ANDREW KORNBERG**, Paediatric Neurologist, on "*Research into GBS/CIDP*" February'03; **SUELLEN COOK** and **DENNIS STURDY**, Centrelink Officers, on "*How Centrelink may help*" May'03 - were informative and led to interesting questions and discussion. Each was published in our newsletter "INformation".

As well, our very helpful computer mentor **GREG KEOGH** kindly adds each newsletter issue on to The IN Group webpage

<http://home.vicnet.net.au/~ingroup/>

Socials

The November Sunday Luncheon Party was again a happy social get-together for 32 members and friends as well as a great fund-raiser. A total of \$848 was raised, including \$295 from the delicious luncheon, \$377 from a Dutch auction, conducted with great fun by **BARBARA BURZAK- STEFANOWSKI**, \$101 from raffles and \$75 was kindly donated from members apologising for non-attendance.

Twenty members and friends enjoyed the Winter Social Luncheon held on 22/6/03 at the Glen

Waverley home of **MARGARET and DOUG LAWRENCE**. Adding to the pleasure of lunching in the delightful surroundings were two musicians, friends of **VILMA CLARKE**, who entertained us, ending with some popular sing-a-longs. The icing on the cake was the \$300 made from the occasion.

Cake Stall Fund Raiser

This now annual event, held at Maling Road Canterbury, thanks to the initiative of Deputy Director **MARGARET LAWRENCE**, and her helpers, was again very successful on Saturday morning 10/5/03. \$707 (including direct donations of \$95) was raised from the sale of many cakes, jam and some produce.

Film Luncheons

A number of our members and friends enjoy from time to time a film and a social get-together over a modest luncheon, held at the Balwyn Cinema. Amongst the films seen were "About a Boy", "Chicago" and "Anger Management".

Grant from Department of Human Services

The Department of Human Services has again rewarded The IN Group for our community support by a grant of \$875 (last year \$850).

The IN Group applied for a grant from the National Bank of Australia's "National Volunteer Awards but without a prize result.

Newsletter "INformation"

This quarterly publication is a vital means of communication to and between members. The Newsletter is yours so make the most of it. Thank you, **MELVA BEHR, DOROTHY BRENNAN, BARBARA CLIFFORD, BETTY GERRAND, FRED HOOTON, MARGARET LAWRENCE, ROSEMARY MACQUALTER** and **BARBARA RIVETT** for help with the mailing.

The National Council in action

Three meetings of the **Council of GBS/CIDP Support Groups of Australia** were held during the year by telephone Conferlink. The Council comprises the GBS Support Groups of North Queensland and of South East Queensland, the GBS Association of NSW, The IN Group of Victoria, and the GBS Support Group of Tasmania.

Office bearers elected at the May meeting were President - **VILMA CLARKE** (Vic); Vice-President ? **GRANT BUCHAN** (Tas); and Secretary/Treasurer ? **MELVA BEHR** (Vic).

The Council again set 1st June as our national **GBS/CIDP Awareness Day**. The IN Group issued a Media Release with the theme "**A Big Thank You to Blood & Plasma Donors**". The Red Cross Blood Service and CSL warmly appreciated this expression of gratitude.

CSL LIMITED was a most generous sponsor with a donation to the Council of \$1,000.

The IN Group Christmas Cards

We sold the packets of our quality IN Group Christmas Cards at a bargain price - 12 in a packet for \$5 ? for a return of \$123, being all profit.

Entertainment Books

Fourteen Entertainment Books at \$55 (\$60 posted) were purchased by members to give The IN Group a quick return of \$154.

Both the Christmas Cards and the Entertainment Books will be available at our November meeting.

Sale of Booklets

We have a steady demand for the GBS booklet published by the US GBS Foundation International and the CIDP booklet published by the GBS Support Group of the UK.

Similarly there is a steady sale for **JUNE CATHCART**'s booklet *Road to Recovery A-Z* and **JOHN POLLARD**'s *Boy, is this Guy sick*.

Thanks

Particular thanks to our Deputy Director **MARGARET LAWRENCE** for her great support; Secretary **ROSEMARY MACQUALTER** for her enthusiastic efforts; to Treasurer **BRONWYN CLARKE** and partner **STEPHEN WALSH** for their rewarding initiatives; and to Committee members **VILMA CLARKE**, **MOLLY GUNTARIK-CAMPBELL**, **PETER MALCOLM** and **BARBARA RIVETT** for their varied talents and sterling efforts in making The IN Group such a continuing success.

JAMES GERRAND,

Director.

The IN Group News

Annual General Meeting

The AGM was held at the Malvern Library Meeting Room on 13/08/03 in the half-hour before the public meeting. Director **JAMES GERRAND** welcomed some 20 members. Following the confirmation of the Minutes for the 2002 AGM, the Director presented his report for the past financial year 2002/2003 (pp 3,4 of this issue), particularly thanking the Committee and the many members for their help and generosity that had made another outstandingly successful year. Following acceptance of the Director's Report, Treasurer **BRONWYN CLARKE**'s Report was present-ed (pp 5,6), setting out The IN Group's Profit & Loss as well as Assets & Liabilities. Generous donations and fine fundraising allowed The IN Group to donate a further \$7,500 to Dr Kornberg's medical research into GBS/CIDP, making a total of \$43,500 to date. The In Group was particularly grateful to CSL Limited for their generous annual sponsorship (1,000) and pleased to be awarded \$875 by the Victorian Department of Human Services for our community health support. The Treasurer's Report was endorsed.

Election of Committee

The following were elected unopposed:

Director: **JAMES GERRAND**

Deputy Director: **MARGARET LAWRENCE**

Secretary: **ROSEMARY MACQUALTER**

Treasurer: **BRONWYN CLARKE**

Committee: **VILMA CLARKE, STEVEN COHEN, PETER MALCOLM, BARBARA RIVETT.**

Support is the Name of our Game

Personal Support

Following advice from member **KEITH COL-WILL** that ex-Governor of Victoria The Hon **RICHARD McGarvie AC** was stricken with GBS in the Monash Medical Centre, I visited him to find he was paralysed in his arms and legs but was slowly recovering. His paralysis had not dampened his ability to communicate. When I mentioned The IN Group supporting GBS patients he joined forthwith. In the day after my visit, from his hospital bed, he spoke to John Faine on his ABC radio program, was interviewed on the TV program, A Current Affair, and had an article published in "The Age" newspaper, all in support of his friend Peter Hollingsworth, then Governor-General.

So Richard's death a week later was a shock to all. I contacted his wife, Leslie, whom I had met at the hospital and she said her husband had died from a clot on his lung. He had been diagnosed with thrombosis some two years earlier. I later spoke to The IN Group Consultant Neurologist Dr **BRUCE DAY** as to whether GBS had contributed to producing the clot. Bruce said the stay in bed from the GBS paralysis from the GBS had probably caused a clot to arise from the thrombosis.

My wife **BETTY** and I attended on behalf of The IN Group the State Funeral held at St Paul's Cathedral on 29th May. It was moving experience in honour of a great Australian who had contributed greatly, as lawyer, judge and Governor, to the community in his 77 years. Celebratory tributes were paid by son, daughter and 15 year-old grandson. The last had composed a song in tribute to his grandfather which he sang and played on his guitar.

IN Group supplying information

We support many people with information about GBS, CIDP and related neuropathies, particularly through being on the Internet. Of the 19 we communicated with, 7 were from Victoria, 6 from interstate - 3 NSW, 2 WA, 1 Qld, and 6 overseas - 5 from USA and 1 from Ethiopia. Eight have become members.

Items from the correspondence;

"? my seven year-old daughter was diagnosed with CIDP when she was two years old and has had regular infusions of gammaglobulin since then, at the moment this is working for her. ?

"It was so nice to find your website, to actually find somewhere where this condition is listed and where I gain information is fantastic. Thanks again."

In my reply I ended by saying I also had CIDP, it had given me "footdop" and I was 84 years old. The mother's reply included;

"Charlotte suffers from footdrop, though she still has very limited movement in her feet. Her main problem is overall weakness, after the infusion she is quite strong but slowly declines over the 6 weeks to her next infusion. She tends to fall down a lot, she has a lot of muscle wastage in her legs

and arms and finds it difficult at times to hold a pencil for long periods at a time which is quite hard at school. She doesn't like to run or do any climbing or sports as she is a bit slower than her friends and not very steady, she definitely does not have good balance! Apart from that she is a very happy child who loves reading and playing with her dolls. When she was first diagnosed she couldn't walk more than 3 or 4 steps without falling down and used to hold on to a wall to support herself while she walked.

Charlotte says to say hello to you, she thinks it cool that someone else has this as well!"

From new member;

Dear Betty and James,

Thank you for sending me my information booklet and newsletter. ?enclosed ? \$41 for subscription, GBS booklet, 2 booklets and donation. I have spoken to Jan Lane (member) from Sunbury and we are getting together this morning for a chat, I am looking forward to it. Thanks for your help, take good care, maybe see you at the November Social Lunch. All the best, Elle (from Benloch).

An overseas communication (Tuesday 05/08);

Dear Sir, my brother's child, three years old, is seriously sick with GBS. We have just been informed the Syndrome on Saturday. First, the doctors were not able to identify it, once identified they were not able to help our child. So, can you help?

Alemu Asfaw, Ethiopia.

My reply;

Dear Alemu Asfaw, If you send me your postal address I will post you a GBS booklet ? plus The IN Group brochure and latest quarterly newsletter "INformation". GBS can be very traumatic but the good news is that most recover particularly when young. Best wishes to the child and regards,

James Gerrand, Director.

We are hopeful of good news.

More blood donors will improve quality of life

This was the prominent headline to a letter published in the Warragul Gazette (21/08) from our member **BARBARA PHILIPPI** of Warragul South who suffers from CIDP. Barbara began her letter;

"I wish to thank Min Weggelaar and all the other wonderful people that donate blood. I am a regular recipient of a blood by product called Intragam.

Then follows some nine paragraphs detailing the importance of Intragam for the medical treatment of a number of conditions including CIDP and how there is a serious shortage of Intragam such that many patients do not receive their required dose. Barbara ends;

I would like to thank the wonderful staff at the hospital where I Regularly receive treatment instead of travelling to Melbourne. We are very fortunate to have such a facility at Warragul.

Thank you to Molly Guntarik-Campbell

Molly decided not to seek re-election at the AGM because of ill-health. The IN Group is very grateful to you and partner Stephen Campbell for what you have contributed as a committee person. You and Steve will always be welcome to attend committee meetings as non-voting members.

News from the NE Cluster

Some members of the NE Cluster and their carers attended a Seminar held at Wangaratta Tafe on "Living Well" with a chronic illness. It covered communication, family, sexuality and hypnosis, and we had the opportunity to listen and ask questions.

Doreen Akkerman, director of the Cancer Information and Support Service at the Cancer Council Victoria, lent her expertise to the day. She has worked for more than 25 years in the provision and development of health information in both Australia and the USA. She is booked out until next year. With much humour she presented the "communicating about sexuality" workshop.

Alison Keir, a local psychologist who has expertise in adjustment to major life changes in long-term illnesses,

was the other workshop presenter.

Also included was a lunch, morning tea, a book stall and give-aways. We had a display of our books, magnets and leaflets and made sure people were "aware" of our neurological disorders. A well-run and helpful day.

"You can't change the wind but you can adjust your sails"

Vilma Clarke - Convenor

Ritchies Community Benefit Card

1% of the money you spend at any of the 26 Ritchies Stores (supermarket or liquor department) with a Richies Community Benefit Card nominated in favour of The IN Group will be donated to The IN Group, if the total spent by IN Group Card holders exceeds \$1,000 in a month (a minimum donation from the 1% is \$10.)

The Stores are located at Aspendale Gardens, Balnarring, Beach Street Frankston, Berwick, Camperdown, Cobden, Cranbourne, Dandenong, Dromana, East Bentleigh, Emerald, Hastings, Langwarrin, Maffra, Mount Eliza, Narre Warren, Pakenham, Ringwood Nth, Rosebud, Sale, Seaford, Somerville, Timboon, Towerhill Frankston, Wantirna, Wonthaggi.

If you think you could benefit yourself and The IN Group by shopping at a Richies Store then contact IN Group Director **JAMES GERRAND** tel 9853 6443, 138B Princess Street KEW 3101. He will arrange the application for your Community Benefit Card. Ritchies will then send you your Richies Community Benefit Card.

DASH

I'M GLAD YOU ARE IN MY DASH---
I read of a man who stood to speak
At the funeral of a friend
He referred to the dates on her tombstone

*From the beginning...to the end.
He noted that first came her date of birth
And spoke the following date with tears,
But he said what mattered most of all
Was the dash between those years.
1934-1998)
For that dash represents all the time
That she spent alive on earth...
And now only those who loved her
Know what that little line is worth.
For it matters not, how much we own;
The cars...the house...the cash,
What matters is how we live and love
And how we spend our dash.
So think about this long and hard...
Are there things you'd like to change?
For you never know how much time is left,
That can still be rearranged.
If we could just slow down enough
To consider what's true and real,
And always try to understand
The way other people feel.
And be less quick to anger,
And show appreciation more
And love the people in our lives
Like we've never loved before.
If we treat each other with respect,
And more often wear a smile..
Remembering that this special dash
May last only a little while.
So, when your eulogy's being read
With your life's actions to rehash...
Would you be proud of the things they say
About how you spent your dash?
If you have received this, it means that you are
truly special to the one who sent this to you.
I am glad that you're a part of my dash..
Send this on to the ones you care about even
if it means sending it back to the one who sent
it to you.*

(Sent by **GRAEME BOLTWOOD**)

[Profit and Loss Report - 2003](#)

[Balance Sheet at Year ending 30/6/2003](#)

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