

[Home](#) | [About](#) | [Newsletters](#) | [INvoice](#)

Physiotherapy in helping recovery

Newsletter No.30 - March 2000

From the address by **MARK HINDSON, Physiotherapist, Austin & Repatriation Hospital Medical Centre** to the quarterly meeting of The **IN Group** held 9/2/00, Balwyn Library Meeting Room, 336 Whitehorse Rd.

Supporting sufferers in



I work in the Acute Neurology and Stroke Unit so a large part of my role is in helping patients with GBS (Guillain-Barré syndrome) and CIDP (Chronic Inflammatory Demyelinating Polyneuropathy). The role of physiotherapy can be divided into three parts - the acute phase, the medium phase of rehabilitation and the long-term, on-going rehabilitation.

There is a patient-centred approach to the treatment of a patient as pictured below.

The important factor is communication with this multi-disciplinary approach with the aim of the team to help the flow of the treatment of the patient.

The Acute Phase

In the acute phase a large part of physio is for respiratory care. With GBS

having the weakness ascending from the feet, once it starts reaching the abdomen and chest then respiratory difficulty can occur with the breathing. If it affects the intercostal muscle - the one between the ribs that lifts up the ribs as you take a breath - we call it a big rib excursion when we take a big breath in.

Equally if your diaphragm is affected - the part of your body between the abdomen and the chest - you have the inability to take a large breath. Usually you are in bed in a hospital when your breathing is compromised with GBS and so you are more likely to catch a "bug" - an unfortunate connection with so many inmates with various disorders.

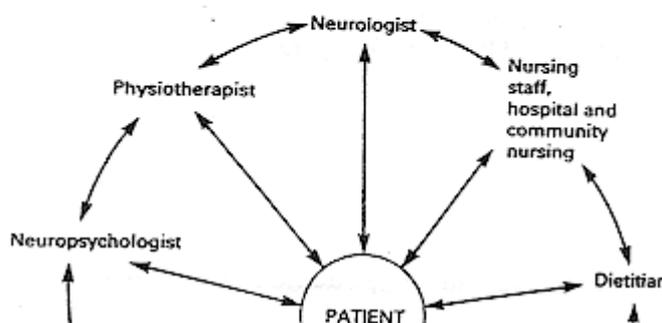
If anyone does contract pneumonia or a chest infection you are involved in treating that. Also you monitor the fatigue levels.

First Phase of Rehabilitation

So then the first part of the rehabilitation phase begins. When we start to get patients moving we have to keep in mind the physiotherapy must be graduated. We realise the patients can fatigue quite quickly and so we try to build up the strength very gradually, deliberately providing a little more demand each time in exercising the respiratory muscles.

An important part of rehabilitation is

The Team



prevention. The positioning of the patient is vital. He/she needs to be nursed so that the lungs are kept clear - from side to side and if need be to be "jacked up" with the head down so allowing any secretion in the lungs to be drained out.

If muscles are kept in a shortened position long enough then there is an increase in the stiffness of the muscle. So there should be "passive" movements, ie aided - through the full range at least once a day. If there is too much movement with weak muscles around a joint, the joint can become quite loose and set up later some pain. Too little movement and you end up with a stiff joint. You can have muscle stiffness and then joint stiffness. This again can become quite painful.

There are available Resting Splints for wrist/hands and for ankles which can be important in the early stages. Tight calf muscles can later on make it more difficult for one to walk, particularly upstairs and downstairs and even on a slight slope. You get too tired.

The important feature at the next phase when you are getting a patient to get out of bed is that his/her circulation is quite dependent on the muscles in the body. There will be swelling in the ankles and hands if one doesn't move around much. So a patient's blood pressure is monitored at this stage to check there is no sudden drop. Such patients wear elastic stockings to push the blood back to the heart and also to prevent blood clots. If the blood sits in the legs there is more potential for clotting. Some patients with weak abdominal muscles may need abdominal corsets.

Once the patient is getting up the whole effect of what gravity has on the joints becomes important. The shoulder joint particularly relies on its muscles around it. He/she may need the arms supported in the early stages of sitting up and walking. It is important to get good seating. If necessary one can make do with a cushion, towel or pillow to support the lumbar spine. Prolonged sitting with a curved spine can lead to small damage to the joints in your upper spine, producing backache. It is similarly important to support the middle and top of the spine as well as the arms.

Stretching the arms including the hands, legs including the feet, body (particularly by slumping), helps to rehabilitate not only the peripheral muscles but also, we believe, the associated nerves. This is important for GBS and CIDP patients suffering from nerve damage. One has to be careful not to overstretch.

Functional tasks of daily living that involve exercise tend to be beneficial. These tasks include walking, repeated sitting to standing, rolling over and moving up and down in bed, putting on and taking off clothes. These tasks help to restore the patient to normal living. A patient may require splints but less bulky ones to make the performance of the tasks possible. One such splint is an Ankle Splint Orthosis - a plastic ankle splint that fits round the ankle in the shoe rather like a shoe horn. As the patient improves these splints can be dispensed with. Each patient tends to differ in their requirements for successful physiotherapy.

Ongoing Rehabilitation

Hydro therapy is fantastic as you can float; so your weight is supported and also you can exercise against the graded resistance of the water - the faster you move the harder it is, the slower the more gentle. It does not suit everyone - some find the heat too much.

It is important to watch the posture as muscle weakness can affect it. IT is often the physio's role to nag and give you advice about your posture.

The patient may need balance retraining because we know the ankles are important for balance. The patient may find the hips have to be moved to keep the balance. What is important is to hone up the ankle muscles as best you can by testing your balance frequently. When you do happen to be startled, say when walking down the street by a skate-bo-arder you can recover your balance. If the

ankle muscles don't recover then the retraining of the hips become important.

Also you still have help from the balance system in your ears and eyes. When you get up in the dark you have one less system to help you.

As you progress then we begin some training in advanced skills of walking up and down slopes and stairs. There are times when you have to quicken your steps such as when crossing a road so it is helpful to have practice in quickening your pace, ie into gentle short running.

As an ongoing practice it is important to have regular exercises to keep stretching muscles that may be at risk of tightening up - calf muscles, hamstrings, arm muscles. Hydrotherapy, walking, exercise bikes or anything that can get your heart rate up are important for ensuring that your cardiovascular and general fitness are in good condition.

One case study reported in the literature is of a patient who three years after suffering from GBS was given an exercise program. The program consisted of 30 minute exercises three times a week for sixteen weeks at 75% of the patient's fastest heart rate when the exercises were begun. The fitness improved by some 20% and strength by some 10%. This showed the room for improvement that is possible.

We Donate \$5,000 for Research

The IN Group on 2/2/00 was pleased to donate a further \$5,000 to assist the research being carried out by Dr ANDREW KORNBERG into GBS and CIDP disorders at the Royal Children's Hospital. This brings the total of our donations over the past four years to \$22,500.

In thanking The IN Group for this donation, Ms Anne Cronin, General Manager of The Murdoch Institute (Incorporating The Royal Children's Hospital Research Institute) wrote:

The continuation and future of many of our vital research programs depends on funds from public donations, gifts and legacies. It is for this reason the Research Institute gratefully acknowledges your support.

The IN Group thanks the many members, families and friends for their continuing generous monetary contributions and personal activities that have made this support a reality.

Forthcoming Events

Cake Stall - Maling Road 13th May

Following another successful Cake Stall last year - \$1,006.70 raised in a few hours - MARGARET LAWRENCE is arranging another fund raiser to be held at Theatre Place, Maling Road Canterbury on Saturday 13th May commencing 10am.

Members and friends are asked to donate their favourite home-made cakes (jars of marmalade, jams and chutneys are also welcome). Please contact BETTY GERRAND 9853 6443 or MARGARET LAWRENCE 9802 5319 to advise details of your donation.

Volunteers to man the stall that morning would also be appreciated.

Film Luncheon

Put this in your diary - I must see "Angela's Ashes" on Tuesday 23rd May at 10.30am to be followed by a nice lunch, all for \$10 (50c goes to The IN Group)

Please note the earlier start (it is a longer than usual film) for an acclaimed production of a best-seller. What better way to see it than amongst the congenial IN Group.

Ring BETTY GERRAND 9853 6443 to book yourself, and/or friends by 16th May.

Meeting Balwyn Library Wed 10th May

Podiatrist JULIE MILLER will discuss "Caring of the Feet" at our regular quarterly meeting to be held at the Balwyn Library Meeting Room, 336 Whitehorse Road on Wed 10th May at 8pm.

Winter Luncheon

Repeating what has become an annual very happy social event, MARGARET and DOUG LAWRENCE invite you, family and friends to their home, 26 Belmont Road, Glen Waverley for our Winter Luncheon, to be held on Sunday 18th June at noon.

For \$10 you will enjoy a delicious light luncheon - home-made soup, chunky bread, dessert, tea or coffee - meet up with members and friends and support The IN Group.

RSVP Betty Gerrand 9853 6443 by Wed 14th June

Entertainment Books

These books cut \$25 or so from your bill at selected restaurants, less formal dining, theatres, sporting events, hotels.

You buy an Entertainment Book from The IN Group for \$50 (\$55 inc. postage). They will be available after April and its use is valid to 1st June 2001. The IN Group makes \$10 from each sale and last year we raised \$135 from their sale.

Order your Book(s) using the wrapper.

Calendar for Year 2000

The IN Group Calendar of Coming Events for the full year 2000 is published on the back of the wrapper.

[not available on the web site yet]

IN Group News

Blood Donors

BRONWYN CLARKE and STHEPHEN WALSH made their own contribution to the Red Cross Summer Blood Challenge by holding a barbecue with 10 friends and then all going to donate blood.

Supply of Intragam still inadequate

AHMAC (Australian Health Ministers Advisory Committee) has still to announce the result of their Working Committee's investigation into the supply of Intragam, now more than 12 months overdue. "Expected next month" is the advice The IN Group receives to its regular inquiries.

The Red Cross is active in encouraging more donations. As one example they arranged blood donations at the Alfred Hospital from staff and visitors on one day in February when I went for my fortnightly Intragam.

IN Group Publicity Magnets

The Committee has allocated \$500 for the supply of magnet cards for refrigerator doors that will display The IN Group logo. Treasurer BRONWYN CLARKE proposed this feature for publicising The IN Group and will arrange the design and the ordering of 500 cards. These will be distributed to hospitals and neurologists.

We have an IN Group Lending Library

The Committee agreed to VILMA CLARKE's proposal to set up a Lending Library of books, booklets, videos, magazines relating to GBS and CIDP. \$200 was

allocated for meeting the purchase of suitable material.

Vilma started the Library at our February meeting and a number of members borrowed items that will be returned at our next quarterly meeting.

Support is the Name of our Game

Outstanding Support through Internet

On the 18/1/00 I received an email from Stephanie Hess, a 22 year-old attending college in Missouri, USA. She had been diagnosed with CIDP in July 1999. Here are some extracts:

"... I am so sick of my current state. I was once an independent person, but because of this I have to depend on others. ... Tomorrow I have to go back to classes after taking last semester off. I took it off because I fell in one of my classes and could not get back up. You would think at the college level people would be more understanding ... but they just pointed and laughed.... I am staying positive and I will not accept defeat.... The ironic thing is, that if I am sitting down I look healthy. A lot of people don't believe that there is something medically wrong with me. .. Any information you could send me would be more helpful than you know. "

I sent her information and also contacted 21-year-old engineering student MICHELLE HUGHES (who members will remember also suffers from CIDP), asking if she would care to communicate with Stephanie by email on the Internet.

Here is Michelle's report 22/2 to me.

"Hi! Stephanie and I have been emailing each other every few days (when our hands aren't too tired!) We have discovered we have a stack of things in common. Apart from having CIDP, we are also the same age, studying similar things and even both have boy-friends named Michael!"

In the first few emails we compared experiences on diagnoses, how it affected our studies and that sort of thing, and swapped embarrassing stories about things that had happened to us. Stephanie was mis-diagnosed quite a few times, with things as unlikely as an inner-ear infection.

Finally being diagnosed with something that has a name was almost a relief, as it was for me.

We also share our treatment experiences. Being jabbed is definitely not high on our "fun things to do" list. Stephanie has different treatment cycles to mine, mine is for two days every month, whereas she has smaller doses more often, weekly at the moment. She also has a nurse come to her house to hook her up.

Stephanie seems to have more severe symptoms than I do, including dizziness and chronic exhaustion. She has recently returned to study but finds it very draining, and also very stressful, sometimes having panic attacks. Some of her teachers are sympathetic, some aren't. I find Uni busy and tiring, but I enjoy it a lot too. I have been working for the last 5 weeks and have found it exhausting. I will be very glad to get back to Uni next week!

Stephanie's also got the added stress of living away from home, with washing and dishes some of her day-to-day struggles. It makes me appreciate living at home!

Stephanie's room-mate recently gave a talk to her class on CIDP, and Stephanie starred as the guest speaker. She was extremely nervous, but said in the end it went well. She said it was great to finally be able to explain what she went through every day, with people finally listening to her and believing her. One guy came up to her afterwards and shook her hand, telling her that he thought she was really brave. I think it had a really good effect on her confidence, much the same as helping out at the blood bank has done for me.

Lastly, we have been talking about the weather. I've been complaining about the incredible heat we've had for the last few weeks, while she's been having SNOW! Not enough to have classes cancelled, unfortunately, but enough to play in.

All in all, it's great to have someone to talk to about how CIDP has totally up-ended our lives. Friends and family are always sympathetic, but it's not the same as talking to someone who's going through it too.

Hopefully we'll keep in contact for quite some time.

Michelle

(We mustn't forget to thank CSL Pty LTD for their continuing financial support for our email.)

[See you at the May Meeting](#)
[JULIE MILLER "The Case of the Feet"](#)
[Wednesday 10th May 2000 at 8pm, Balwyn Library, 336 Whitehorse Road](#)

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