

PHYSIOTHERAPY

At some point in our lives, many of us will seek the services of a Physiotherapist – for a nagging back problem or sports injury perhaps.

But when you are living with MND, the help and support passive physiotherapy can offer can make a major difference to day-to-day living. People with MND may develop varying problems with mobility. Those everyday things we take for granted – sitting comfortably, climbing stairs, getting in and out of bed – can all become difficult as muscles weaken, and the disease progresses.

That is where passive physiotherapy can be extremely helpful. Many people with MND want to preserve their optimum level of mobility for as long as possible. Exercises in the early stages can improve muscle function, though exercise involving strong resistance should be avoided. And as the disease progresses, the passive Physiotherapist can help people achieve as full a range of movement as possible. Exercises that help alleviate spasticity, pain and stiffness as well as help prevent muscle cramps and joint deformity can make a considerable difference to quality of life.

For people living with MND, passive physiotherapy can be useful in a number of areas including helping to improve balance, posture and co-ordination. Many of the exercises suggested by a passive physiotherapist can then be done at home by the patient, often with help from a carer.

Many people with MND understand the importance of passive physiotherapy and are very committed to doing as much as they can to maintain some level of movement and mobility for as long as possible. Occupational Therapists can arrange for a more supportive chair to be provided, as well as recommend different types of exercise, teaching relaxation techniques and breathing exercises.

Rest and relaxation are vital for people with MND. All types of exercise can be quite tiring and it is important for patients to find their own strategy for relaxation.

Physiotherapists work together with their patients to develop ways of adjusting to the mobility problems MND may bring:

- Help you plan an exercise programme that is right for you
- Improve your balance, posture and co-ordination
- Help reduce muscle stiffness and discomfort
- Give advice about walking aids
- Give advice on splints, collars and braces for support.

TIME FOR A SMILE !

Imposter Brunette

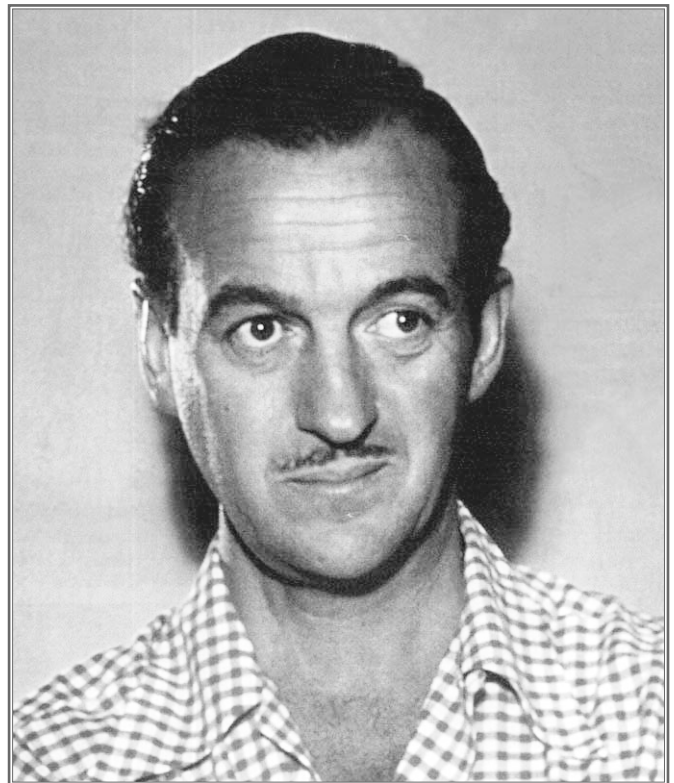
A young brunette goes into the doctor’s office and tells him that her body hurts whenever she touches it. “Impossible”, says the doctor. “Show me”. She takes her finger and pushes on her elbow and screams in agony. She then pushes on her knee and screams, pushes on her ankle and screams and so it goes. No matter where she touches, her agony is apparent. The doctor says, “You’re not really a brunette, are you ? You’re really a

blonde”. She sheepishly admits that she is indeed a blonde and asks, “But how did you know ?” “Because, my dear” he says, “Your finger is broken”.

RESEARCH

A considerable amount of media attention was generated overseas recently by news of an experimental treatment for MND, using stem cells from human umbilical cords, which was being advertised on the Internet. After examining the clinic’s website, the UK Association expressed certain reservations. The limited results claimed were based on initial studies only; the findings reported to date were partial and preliminary, and the collective results demonstrate the efficacy of the procedure are not yet known.

Following consultations with a leading UK neurologist, a statement was issued playing down the likely significance of the treatment and advising people with MND to talk to their neurologists before committing substantial sums of money to participate in experimental studies.



David Niven, the inspiration behind the Thumbs up sign

David Niven, the Hollywood actor, lost his fight against Motor Neurone Disease twenty years ago. We are keeping his hope of finding a cure, alive, by continuing to give support and advice to those living with MND and keeping abreast of overseas research.

Please kindly remember the MND Association in your Will. You’ll be giving hope to future generations and helping to fulfil his wish.

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Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



Sue Giddings and Peter Mettleford in the Pick'n Pay/Argus Cycle Tour

**The Mission Statement of the MND Assoc. of S.A. is
"To provide and promote the best possible support for people living with
Motor Neurone Disease, their families and carers and to raise public awareness."**

NEWS and REVIEWS

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Aviva Pelham (M. Mus.)

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Dr. Peter Kraus

VICE CHAIRPERSON
Vivien O'Cuinneagain

TREASURER
Bunty Money

SECRETARY
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Dear All

The season may have changed. It may be bitterly cold in some parts of the country but at the MNDA we have a new solar force. Joining our team is Liz Keth, a nursing sister who will be running operations in the Gauteng area. We wish her well and many happy years with the patients, their families and the Association. She has wasted no time establishing herself and getting stuck in. Some of you have already had the good fortune of meeting her.



Liz Keth, a nursing sister who will be running operations in the Gauteng area

Our numbers continue to increase, and our next step is to employ a nursing sister in the Durban area. The goal of the Association will always be to increase care and support for patients with MND and their families. We need to strive to create more public awareness.

As usual I am sitting at my desk studying – this has become an almost full time occupation. However, recently I read a book on the spiritual wisdom from the Celtic world and in closing I share this poem with you:

A blessing for the senses

May your body be blessed.
 May you realise that your body is a faithful and beautiful friend of your soul
 And may you be peaceful and joyful and recognise that your senses are sacred thresholds
 May you realise that holiness is mindful gazing, feeling, hearing and touchin
 May your senses gather you and bring you home
 May your senses always enable you to celebrate the universe and the mystery and possibilities in your presence here
 May the Eros of the Earth bless you

*Spiritual Wisdom from the Celtic World
 John O'Donohue*

Life is a mystery, it is a journey – make the most of the here and the now.

Dr Peter Kraus.

NEWS

Ken Shuter, a patient living in Magoebaskloof, was diagnosed with MND about 3 years ago. He was a teacher of Art and English and has a great passion for the outdoors. He was a gymnastics coach, parachute instructor, ski instructor in Austria, a wilderness trails officer, swam 12 Midmar miles and ran 7 Comrades.

He is now confined to a wheelchair and has the most fantastic support from the local community, even to the extent that they have established a Trust Fund to cover the expenses for his care. When he expressed the wish to do another Comrades Marathon, his friends rallied around and organised exactly that. They devised a “push-pull” team of 32 runners and a support group and on Saturday 29 March 2003 they set off from Pietermaritzburg City Hall for the down run. This was all filmed by Carte Blanche and broadcast on Sunday 6 April 2003.

His attitude to life is very positive. In his own words “The past is past, the present is a gift and the future is a miracle”. He is an inspiration to all of us.



Ken Shuter and support team running the Comrades Marathon

Subsequently his support team organised a gala dinner with Bruce Fordyce as patron.

Pick'n Pay/Argus Cycle Tour

Sue Giddings and Peter Mettleford took part in the Pick'n Pay/Argus Cycle Tour wearing the MND logo. They also handed out some of our “What is it ?” brochures and thanks go to them for creating the awareness. Following their efforts, we have had many offers of support from the public. If anybody would like to spread similar exposure please let us know. Your efforts would be greatly appreciated.

Networking

The International Alliance was contacted by Yves Martin who operates an organisation called “La Chainette” which is a networking chain linking people with the same or similar uncommon disease and providing a networking opportunity through the Internet.

You may be interested in making people living with ALS/MND aware of this website. It may also be of interest to those who have been diagnosed with Kennedy’s Disease or X-linked Spinal and Bulbar Muscular Atrophy.

The site is <http://www.networkchain.org>

GLOBAL AWARENESS DAY WILL BE SATURDAY 21 JUNE

The Chat Room is at www.alsmndalliance.org – click on Other Links, and then on the link to the Chat Room. Alternatively, go straight to

<http://www.alsmndalliance.org/chatforum/phpMyChat.php3>.

Internet Chat Times

Melbourne, Aust	Los Angeles	London	Rome
9.00 am	4.00 pm 06/20/2003	12.00 midnight	1.00 am
Midday	7.00 pm 06/20/2003	3.00 am	4.00 am
4.00 pm	11.00 pm 06/20/2003	7.00 am	8.00 am
8.00 pm	3.00 am 06/21/2003	11.00 am	midday

Look forward to catching you on the net

It is with deep regret that we advise the very sudden passing away of Bubbles Erasmus on Saturday 31 May 2003 and our condolences go to her family. Bubbles was a volunteer caregiver in the Gauteng area for a few years. She will be sorely missed by all with whom she came in contact.

A tribute to Bubbles from a patient, Danny Savage:

She unselfishly gave her time to helping the frail people in the Hospice and those who suffer from MND. I will miss the encouragement and help she gave me. She was there for us all, and my condolences to her husband and family.

May her dear soul at the mercy of God rest in peace.

Condolences to the Family and Friends of:

Julie Bravo; Isak Sonan; James Lawrence; Vivian Davies;

Gregory Magiera; Eugene Kritzing; Jakobus Beukes; Ethel Naude; Edward Ngigi Kinyanjui; Marie Grobler; Jessie Birss; Audrey Britz; Peggy Price; Roger Jimenez; Martha Percival; Mr Francis Eagar.

ANNUAL GENERAL MEETING :
Wednesday 27 August 2003
at Pinelands Village Community at 8 pm. ALL WELCOME

MEMBERSHIP RENEWAL FORMS
are included in this newsletter

MNSA FORUM

Ishwar Naik writes:

I am in my ninth year of MND and I really would have loved to attend the dinner for Ken Shuter, as I know the area of Haenertsburg well, with its quaint village, azaleas and cherry blossom season, but with moving house at that time, could not quite fit it in. He has my prayers and blessings.

Wynand Herholdt is a retired academic staying midway between George and Mossel Bay in Hersham Beach, a suburb of Great Brak River. Wynand was diagnosed with MND in October 2001 and is wheelchair bound since September 2002. Staying in a double storey timber house Wynand had the challenge to get to the first floor in his wheelchair. The commercial options of wheelchair lifts were too costly and he could not find an example of a DIY version.

At his wits end, Wynand decided to "do-it-himself" and designed a trolley lift to fit the timber stairs in front of his home. The construction was done by his neighbour (a retired boiler-maker)

The material used was comprised of the following: 18 meters (40 mm) angle iron; four meters (20 mm) square tubing; 1 meter (10 cm x 5 cm) channel iron; 1m² (25 mm) plywood board; four poly-urethane trolley wheels (10 cm diameter); nine meters (6 mm) galvanised steel cable; two 8 cm pulleys; a two-way manual winch (1:7); coach screws, bolts and nuts, and cable fasteners. All metal parts were galvanised to prevent rusting. As can be seen on the photo a 1m³ hole was made at the bottom of the stairs for the trolley to be lowered into, in order to get the trolley platform on ground level to enable the wheelchair to be pushed onto it. For the system to work Wynand needs the help of one person (usually his wife Ingrid) to operate the winch.

Anybody interested in detailed information is welcome to contact Wynand at 082 3746466 or at wynandh@lantic.net

JULIE BRAVO – A BRAVE SOUL

(From Graham Miller, her brother)

Sometimes life-changing events can strike any of us at a moment's notice. It was this shock that dawned on Julie Bravo when her husband Attilio was taken suddenly ill and rushed to hospital on 18th January. He died on the following Tuesday. Attilio had been heroically caring for Julie for the past two years. Julie has motor-neuron disease.

Julie retired on pension from First National Bank, Rosebank branch three months before the first symptoms of the disease appeared. In her case a dropped left foot was the first indication. Julie had been with Barclays and First National Bank (FNB) for nearly thirty years. She had all sorts of plans to travel overseas to Italy and Britain, and in South Africa. She bought a new car and started making plans to do part-time work in her retirement. – What hopeful days those were !

MAIL BAG

Attilio at 74 years, worked from home and used his knowledge of the Fiat truck motor industry to locate spare parts and to give mechanical advice to transport operators. He had worked for Fiat and Fiat agents in his career before retiring.

His funeral was held on Saturday 25th January. Julie decided that she would attend the church service despite her totally bed-ridden condition. Her son-in-law Adrian Stander and her daughter Bernadette arranged with Netcare 911 at Sunninghill Hospital to provide an ambulance to transport Julie from Jabula House, Rivonia where Julie is in frail care, to the Cedars of Lebanon Catholic Church in Woodmead. Well, everyone rose to the occasion in spectacular form and Julie, on her Netcare stretcher, arrived at church ahead of the main congregation.

Many people came over to greet Julie and offer condolences, which she acknowledged with a thumbs-up sign. This is the international positive sign of Motor Neuron Associations all over the world. You see, Julie has not been able to talk for nine months. The reason for the stretcher is that she can move only her right hand and head. Her mind is absolutely crystal clear as the twinkle in her eyes will tell you.

Julie gained a great deal of strength from the closure that Attilio's funeral service provided. Her daughters Teresa, Angela and Bernadette, supported by their husbands, have cared for Julie in her time of need and recently for their father when he was ill. There has also been wonderful, compassionate support from the organisations mentioned above, not forgetting the regular visits by sisters from Hospice and the MND Association. Julie radiates when people arrive. She is aware that it is difficult for visitors to know what to say but her smile soon puts you at ease. She just loves a few minutes of their presence and some encouraging words.

The onset of this dreadful disease known as Motor Neuron Disease (MND) is more widely experienced than the public is aware of. In fact most people do not know of it. The progressive effect of the disease is to slowly render ineffective the nerve connection between the neurons in each muscle and their corresponding neurons in the brain. The medical profession is researching this disease world-wide and needs more funds. They do not know what causes the disease and there is no known cure or treatment.

Although this is a very sad tale, it is also a story of courage, fortitude and love. Attilio used to jokingly say when they were married in 1960 that he hoped this young (Julie is now 62 years) English girl would look after him in his age old. – Well, it was he who looked after her with love and care for as long as he was able. Julie says a big "thank you" to those who are helping her and gives her love.

(Sadly, Julie has since passed away).