

Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa

February 2008



*Enjoying the fresh air while having lunch -
Patients from the Cape Town Support Groups on an outing to see the
"famous flowers" of the West Coast.*

**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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MNDA of South Africa is a member of the International Alliance

ACKNOWLEDGEMENTS

John Hall for producing the design and DTP (desk top publishing) work.
Logo Print (Maitland) for the printing of our magazine

We wish all our readers a happy, safe and peaceful 2008 !

It is 10 years ago that the first edition of "Thumbs Up" (February 1998) went out to our members. As the saying goes, a lot of water has passed under the bridge, and although a lot more is known about MND than ten years ago, research has, sadly, still not brought any significant breakthrough.

It seems like a very long time since we last had contact (September 2007) and hope this will be an interesting edition.

We have in the last year tried various ways to raise the desperately needed funds to cover our expenses, eg increased our membership fees from R50 to R75 per annum, and requested patients, families and friends to apply for a Woolworths Supporters Card. Unfortunately the latter has not been successful as we did not receive the response we were hoping for – which was to at least collect the initial 200 applications we needed to partake in the scheme. The membership fee increase has also not made a difference.

We had a show at The Theatre on the Bay in Camps Bay (CT) for MND Global Awareness Day on 21 June, 2 shows at the Barnyard in Broadacres (Jo'burg) and a Golf Day where the MND Association was one of the beneficiaries - but this just covered our expenses for those months.

Our "piggy bank" is empty, and our expenses far exceed our income. We could go on and tell an even longer sad story but it all boils down to that (often regarded as dirty) but O so essential a commodity – MONEY. We need sponsors, large regular ongoing donations, legacies and bequests – in other words we desperately need your help !

The Association is in dire need of funds to continue with the care and assistance we want for our patients. We wish to also establish support groups with nursing consultants in other areas like the Eastern Cape and KwaZulu-Natal – but we do not have the financial resources to bring our plans to fruition.

Our ultimate aim is to acquire a property, where we can accommodate patients on a respite care basis, house our office, store our equipment, train volunteers and have support group meetings. But this seems like an "unreachable" dream so - PLEASE HELP US BY SUPPORTING

OUR NEXT FUNDRAISER**The Oscar and Tony Awards hit Musical****"CABARET"****At the Artscape Arena Theatre, Cape Town****on****15 MAY 2008 AT 8PM****This is a very well-known and popular show and you are advised to make bookings early !!****Tickets at R120 obtainable from Roxy on 082 468 8980****Or e-mail : levy@headsouth.co.za*****"Life is a cabaret, old chum – come to the cabaret"*****DONATIONS****Donations received since our last newsletter:**

PM Snyman (Monthly), R Els (Monthly), G Subotsky, Jack Carstens, JA Milner, GR Scallan, GC de Bruin, AA Carrim (Monthly), Mandy Snyman, S Eigenhuis, S van Blerk & E Evans, WA Swan, F Rosalen, Martin van Niekerk, Rabie Properties, GA Jordens, Masonic Bowling, GJJ van Vuuren, Victor Demelo/Anchor Yeast, Janie Zaal, E Arndt, S Derman, G Conradie, Estate Late UM Tommasi, Philip Schock Trust, J Buchanan, Des Munroe, The Adele Searll 100 Club, HF Swanepoel, I Naik, R Hollings, R Jowell. A big thank you also to everyone who added that little bit extra to their pay-

ments for Christmas Card orders.

To The de Kock couple who recently tied the knot, thank you for your very generous gesture in donating a substantial sum in celebration of married life. May you be blessed with a long, happy and successful future together.

A special thanks to Mr Laurie Chiappini for his generous contribution which enabled us to treat patients at the various Support Groups to an end-of-year gettogether.!



Patients from the Helderberg / Somerset West Support Group enjoying their Christmas Get-together



At the Christmas Get-together, patients from the Southern Cape District, enjoying their outing to a restaurant in Oudtshoorn.

Shirley Levitt of CapeTown, whose husband Charles passed away last year, sent us the following e-mail:

Hi, thanks so much for your very interesting magazine received.

I would like to share this with you : My daughter Taube Levitt, a therapist in Irvine LA, and previously a social worker in Cape Town, dedicated a working session day, in her father's name, Charles Levitt, who passed away on 1 February 2007.

She organised 30 children whose parents had Motor Neurone Disease known as ALS/Lou Gehrig disease in the USA. They had a treasure hunt – to find plasters – symbolising to stick together, and cotton buds, for hugging. Then the younger children made puppets from paper plates – showing happy/unhappy faces, all the children, also on paper palms, wrote special messages to their parents. This was stuck onto “palm trees” which were put up for all to see.

The children also blew up balloons- this is to show/express their feelings because the balloons can burst if too full – it is for them to express their feelings ! Afterwards they had refreshments and rock climbing.

Martin van Niekerk of Centurion, sent this letter:

My dear wife Maureen lived with MND for the last number of years of her life and passed away on 4 November 2006. In memory of her and in grateful thanks for what the MND Association, and in particular Liz Keth, did for her during that period I am making a donation to the Association.

Maureen and I, the caregiver, were always encouraged and inspired by Liz during her monthly visits to us and we appreciated all that she did to make life a little easier for us. In closing I would encourage you to keep up this wonderful service to all those who would be lost without it.

Ntsadi Patience Motsuenyane of Rosslyn, Pretoria, writes:

My family and I would like to express our sincere and deepest gratitude to Liz Keth and the MND Association of South Africa, for the love and support they have shown throughout my late husband, Phule Solomon ‘Thabo’ Motsuenyane’s battle with MND, till his death on 4 September 2007.

My husband first got sick in 2003, and was diagnosed in 2004. It was a long and very difficult road, as we went to different doctors and tried so many different ‘alternative treatments’ without success. During this difficult time, we received support from Liz. She visited us, offered advice, and brought us various items of equipment to make life a little easier for us. Despite his weakening body and gradual disempowerment, Thabo remained positive and optimistic and put up a brave fight. He continued working (despite being wheelchair-bound and not being able to write) until the day he was admitted to hospital on 31 August 2007 with respiratory problems.

I have nothing but admiration for my husband’s fighting spirit and his will to live. I feel blessed to have had someone like him in my life. He was larger than life, touched many lives and was truly “A giant on whose shoulders others could

stand” – He was one of a kind.

Once again, thank you Liz and the MND Association for your support. May the good Lord continue blessing you for the wonderful work you are doing.

Patient Dr Andrew Steyn of Somerset West writes:

MND can also be less formidable.

I have always been reluctant to talk about or of dwelling on my condition, but because I am one of a very few fortunate patients, I have decided to give some insight into the course and progression of my illness.

I was diagnosed with Motor Neurone Disease at the Groote Schuur Hospital in 1993. There were also signs a few years earlier which almost certainly could be attributed to the onset of the condition. I have therefore been living with MND for at least 15 years. An exceptionally long time and I consider that my quality of life is still fairly good. I cannot walk unaided anymore and am very easily fatigued. I also experience some difficulty in swallowing, but am able to handle this if I am careful.

Briefly, something about the way in which I treat and manage my disability: Since there is presently no specific treatment for MND, I am just taking some anti-oxidants and vitamin and mineral supplements. I also try to get a bit of exercise, but because of the rapid onset of fatigue, it is very minimal. I am fortunate in having all possible aids. Some were supplied by the MND Association. I am also very grateful for having an able and patient caregiver in the person of my wife, Ziska.

This case illustrates that, although Motor Neurone Disease remains a very serious illness, diagnosis of the condition does not necessarily mean very severe incapacity and short term death sentence.

In conclusion I would like to mention that I believe my prayers and those of others have greatly been responsible for the exceptional course and progress of my illness. “More things are wrought by prayer than this world dreams of”.

Molly Ngcula of Guguletu, passed away in St Luke’s Hospice and his wife Pauline Ngcula and family wrote to us:

We would like to thank you for your love and care, the equipment which made life easier, the newsletters which we enjoyed to read and the birthday cards we received that put a smile on his face because of the wording. He even received one after his death, he must be smiling wherever he is.

We have no words to thank you. May God bless you all in your work and may He show the researchers the cure. We love you all.

“Let us be grateful to people who make us happy.

They are the charming gardeners who make our souls blossom” - Marcel Proust)

(Sent to us by Mandy Snyman, PE)

Christiane Stander of Centurion tells us her story

“My fifteen months as a caregiver... ”

Motor Neuron Disease or MND, the incurable degenerative neurological disease made my mother-in-law a prisoner in her own body. This monster disease made its appearance around November or December 2005 when her speech began to slur and her left hand was not functioning, as it should. At first everyone put it down to grief and loneliness because in September 2004 my father-in-law passed away very unexpectedly from a heart attack leaving her to live alone in Mosselbay. Being the stubborn old lady she was she would not go to the doctor and told us she would heal herself.

We noticed that her speech became more and more slurred especially when she was excited, tired or emotional. And then the muscle twitching started, first in her left hand and arm. These twitches are called fasciculations and are a trademark of motor nerve irritation.

At first she could not perform small tasks, and also walking became a problem because she would fall down often. She started to use a walking stick, but by this time her left hand and arm were totally useless. She could no longer cope by herself and we moved her up to Centurion in July 2006 when she came to live with us.

We took her to the neurologist who did all the necessary tests and finally he gave us the bad news. Motor Neuron disease was the diagnosis; it was like being given a death sentence! I felt totally numb and shocked, if I felt like that I couldn't begin to imagine how my poor mom-in-law must have felt.

He tried to explain the disease to us in laymen's terms and it was something like this. “In MND the neurons in the brain no longer communicate with the muscles. Tighten those biceps, the brain might instruct, but the message never arrives. Eventually the muscles, figuring they are no longer required, deteriorate. The muscles for speaking and swallowing called the bulbar muscles are also affected. Failure of the diaphragm muscles that control the breathing is usually the cause of death.”

When life handed me the responsibility of caring for someone with Motor Neuron Disease, it forgot to give me an instruction manual. I was unprepared, stressed and often emotional, having often to cope with these burdensome physical demands. My life had changed drastically regarding both family and social issues. I often felt unable to cope with the huge chore, almost 24 hours of every day, seven days a week I was with mom-in-law and responsible for her.

I left my plans behind to meet her needs. This care giving business was in fact a long-term commitment and I often wondered whether I would succeed.

Speaking was a major problem and she battled to make herself understood, her lips were too weak to form the consonants

required for basic words. I quickly adapted to her manner of speaking and was able to understand and translate for her. I was her caregiver and communicator.

Almost every day I felt a tremendous sense of grief at seeing my mother-in-law waste away like that, “a butterfly with broken wings” I would think. But I would not be totally honest if I didn't tell you that there were also days when I thought to myself “I hate this ... I can't take it anymore!”

There were times when I resented the fact that I have had to put my life on hold and neglect my own needs so that I could cope with someone else's needs. But on those days it seems that God was aware of my struggles and He gave me the strength to carry on.

When the hugeness of this responsibility would overwhelm me I tried not to look at the large picture, instead I broke the job into small chores. I would change the sheets and make up the bed without thinking about what comes next. Afterwards I would focus on the next task. I took it one day at a time, one hour at a time, one minute at a time.

Freedom is something we all take for granted. A trip to the supermarket, a visit to the hairdresser, or even buying stamps at the post office can all be done by anyone. Yes, that's quite true, that is until there is someone in the house that requires twenty-four hour care. That's when you really start to feel alone in a world where everyone has shut the door and suddenly you cease to exist in society.

We are all creatures of habit, and the same can be said for a household and family unit. We all have unique habits, traditions and expectations. There is a sense of safety and assurance in this process. So when something so enormously tragic and terminal struck us, everything changed and our lives were an upside down mess. We were tired and distracted and because of all the interruptions I often forgot what I was doing so there were many loose ends. Once the milk was in my office next to the computer and that was how I knew that my specs (which I was looking for) were in the fridge.

Family members become scarcer and scarcer because they're afraid you'll ask for help, and they leave us to do everything. When they do decide to show up for a visit they expect either a cooked meal or tea and biscuits. Our home is a very sad one at the moment because every day we face the fact that MIL is dying. There is absolutely nothing we can do about it except to make her as happy and comfortable twenty-four hours a day every day of what is left of her life. This illness is not her fault, and I know that she would love to have her grandchildren and great-grandchildren visit her more often, instead their visits become shorter and further apart.

She had a couple of falls and after each fall she never fully

regained her strength or confidence. By January 2007 she had decreased mobility and was mostly dependent on the wheelchair.

It became increasingly difficult to leave her on her own and decisions needed to be made about her care. Carl and I could not be there 24/7 and we decided to get care workers to help. Sounds easy? Well take my word for it, it was the most unpleasant way to live. We had strangers in our home, sleeping in our living room and generally taking over our lives 24 hours a day every single day and we became outsiders in our own home. Very often she did not want the care worker to help her so I washed her, dressed her and helped her with her toilet needs, Carl lifted and carried her, took her to the bathroom and pushed her chair and yet she fought us every step of the way.

She spoke a language that by then even I struggled to understand and at the end it was like taking care of a child. She did not want to go out of the house or be bathed or fed. She cried and wailed if we forced her to do anything and her face and eyes were full of fear.

Our health was also declining and we were living in a time zone of depression and despair. When a space became available at a frail Care centre she was happy to go. Every visit was overshadowed by her discontentment. We tried to make her happy but it was difficult. When we left she was angry with us rather than happy that we were there. She often glared at us and ignored us. I knew it was her illness that made her that way and being agitated and difficult was the only way she could express her distress and frustration at being trapped in her body. Still whenever I left her room tears would be streaming down my face. I no longer felt strong and in charge like I did when I began to care for my mother-in-law. I felt lost and lonely like I was not doing enough, even though I was doing all I could physically and emotionally.

I am so grateful for my sense of humour. It helped to relieve a lot of tension and anyway laughing is good for everyone physically and makes us feel better. I'm sure that some people would think, "how can anyone laugh at a time like that?" Studies have proved that laughter boosts the immune system lowers the blood pressure and releases endorphins in the brain that makes us happier and healthier.

My advice to others would be to stick by your loved one, no matter how hard things get, because dealing with this illness can be the hardest thing you might ever have to face in your life. God gave me that responsibility; He could have given it to someone else, but somehow he saw some kind of quality in me that he thought was good and placed her in my care so that she would not be alone in this gruelling challenge.

Caring for my mother-in-law made me discover a lot about myself that I didn't know was there. I've discovered that I have a great capacity for love and sacrifice; I have strength of character and staying power. I am thankful that God has given

me this opportunity to grow in character and spiritual depth.

My motto was this: "Wake up each day with the knowledge that you have the power to make the day into anything that you want it to be. It's not that there won't be stressful situations put in your way; it's saying to yourself that you have a choice of how to react to those situations. A positive attitude and a happy smile can do so much to brighten the lives of those around you."

Good luck and God Bless!

Christiane

"Life may not be the party we hoped for, but while we're still here

we may as well dance"

(Mandy Snyman, PE)

RESEARCH

**(Extract from the Autumn 2007 edition of Thumb Print, UK)*

Thinking and Behavioural changes in MND:

For many years it was thought that MND only affected the nerves which enable our muscles to move. However, increasingly, research is concerned with the subtle changes that occur within the structure of the brain itself. Specifically the areas of the brain concerned with the ability to think, reason and remember.

This research indicates that symptoms of changes in cognition may range from very slight, almost minimal disruption to function and ability to, rarely, a form of dementia.

What is Cognition ?

The word cognition refers to our brain's ability to think, understand, learn, reason and solve problems. We all know the need to pay attention and concentrate in order for us to learn and understand things. As with any aspect of our brain function it is highly complex and involves many areas of the brain. It is thought that up to 60% of people with MND may show some degree of cognitive changes. Cognitive changes related to MND can have an effect on the individual's mood, behaviour and sometimes language, especially word finding and verbal fluency.

Research also indicates that approximately 3% of people with MND develop a type of dementia called Frontotemporal Dementia (FTD).

FTD does not usually lead to memory problems often associated with other types of dementia such as Alzheimer's. Symptoms of FTD include inappropriate behaviour, loss of insight and ability to empathise with others.

It is inevitably going to be distressing to find out that you may have another symptom to deal with. However, knowing more about the disease, and understanding why a person is behav-

ing in a certain way, can help everyone cope. Knowledge and understanding are powerful tools in managing your life with MND.

Are there any other factors that could be causing changes to thinking and behaviour ?

Depression, anxiety and stress can lead to temporary cognitive changes. These emotions are often experienced by the person with MND at various stages in the disease and can be treated in a variety of ways.

Some medications can have an effect on thinking and behaviour. If you have noticed changes since taking any new medication they may be related. Talk to your GP about any concerns you may have. It may be possible to try an alternative form of the medication or it may be that the changes will go away after your body has adjusted.

People with MND who experience breathing problems may also notice a change in their thinking and or behaviour. Effective management of your breathing problems should alleviate these changes.

Finally, as MND tends to affect people from middle age and onwards there are the normal age-related cognitive changes that we will all experience to some degree or another.

Your GP or Consultant will help you to work out whether any of the above reasons are causing the changes you are experiencing.

What can I do if the changes are related to my MND ?

There are a number of things your carer and family and friends can do to help you – share the following ideas with them:

Coping day to day

- Keep to routines where possible
- Keep frequently used items in the same place
- Be aware of the difficulties the person may experience when taking on new tasks
- Split tasks into simple steps
- Offer limited choices to avoid overwhelming the person
- Use simple lists, diaries, notebooks, prompts and reminders to help maintain independence
- Try to avoid situations that lead to confrontation and stress
- Avoid/minimise distractions when communicating

If you are experiencing cognitive changes it is even more important for professionals to ensure they consider the effects of the disease on both you and your carer. Talk to professionals involved in your care about the changes you are experiencing and how you prefer to manage them. This in turn will help them to offer the best way to manage the physical changes of

MND.

Key Messages

- Thinking and behavioural problems can be a symptom of your MND
- It is important to seek advice from your GP or Consultant
- Let your family and friends know how they can help you

A World free of MND

*(An extract of a presentation by Prof Pam Shaw at the recent Annual Conference)

Prof Pam Shaw is Professor of Neurology and Head of the Section of Neuroscience at the University of Sheffield. Her achievements in MND have been recognised in many prizes, awards and honorary positions.

In her presentation Prof Shaw gave an overview of the current knowledge on motor neurone degeneration and explained how this knowledge is being used to develop new drugs for clinical testing.

Pam talked about the different models used for studies, such as mice and zebra fish and how they give us clues on why motor neurones degenerate. We need to find out why the motor neurones become injured and why certain groups of motor neurones, such as the ones which control eye movements and pelvic floor muscles, tend to be spared.

Pam outlined gene expression profiling and gave examples of how this has helped advance our knowledge in other disease such as Leukaemia and Huntington's.

"I'm very excited by the prospect of gene therapy which just ten years ago seemed like science fiction, but recent technological advances are bringing it closer to science fact."

Pam believes that it holds more promise than stem cell research which is still in very early stages.

So What Next ?

Fight the little monster in my body as much as possible, with the help of Family & Friends.

Remember they are hurting too

Pray for them and for yourself

Look at yourself in a mirror and against all odds, DON'T

GIVE IN

Every hour is precious in our lives

I am finding I am planning my future (getting things in order)

Thank GOD for the life I have had before MND struck.

LOVE and PEACE to all my Fellow Sufferers.

*(Joyce Elliott, Blackburn)

(Keep only cheerful friends – The grouches pull you down !)

Elastic Shoelaces

Turn a labour-intensive tie shoe into an easy no-tie versio with elastic shoelaces. Tie your shoelaces as you normally would and then let go, or use the spiral type and don't worry about tying at all. No bending over to fumble with the laces – just slip them on and your on your way. Other types of closures for your shoes include Velcro.

Buttonhook

The buttonhook might take care of all your buttoning problems. If you find yourself fumbling to grasp the button, just slip the hook through the buttonhole, then catch the button and pull it through the hole.

Writing utensil grips

Get rubbery slip-ons for your pens and pencils at any store where school or office supplies are sold. By providing you with a wider and better grip, they ease the strain on your fingers. You can also buy pens that come equipped with a grip. Pens with felt tips, rolling balls or gel ink require less pressure to put ink on paper and tend to write more smoothly than other pens.

Book-holder

Use a book-holder to prop up your book while keeping your hands free. The book-holder saves your hands from the pain of grasping your book for long periods of time and reduces the strain on your neck created from looking downward.

Disabled Travel

(info@disabledtravel.co.za) www.disabledtravel.co.za

- For all you want to know about travel and accommodation – where to go and what to do - in and around our beautiful country,

contact Karin at the above links.

- A “Wheels and Runners” race is being organised on 3 May 2008 in Hermanus.

Telephone : 028 312 1889 / 082 923 3201

“Rolling Inspirations”

Is a lifestyle publication for people living with mobility impairments, disabling conditions, etc and neurological disorders.

Their mission is to be a “must-have” publication for all mobility impaired and those around them and to keep them abreast of product developments, lifestyle, trends, etc as well as medical care and technology.

For more information and/or subscriptions, contact Karen Joseph 083 259 0208.

Remember –

Life is not measured by the number of breaths we take,
BUT by the moments that take our breath away.

Condolences to the Family and Friends of:

Molly Ngcula, Joyce Scallan, Joan du Toit, Sarfia Mohammed, Douw Crouse, Phule Motsuenyane, Alfred Mali, Lois du Toit, Corrie Stander, Robert Zanders, Johan de Waal, Thomas Janse van Vuuren, David Watson, Robert Matupi, Ben Odendaal, Rod Whelan, Ted Thomas, Pieter Ferreira, Kevin Hunt, Maxie Wagenaar, Andries Visser, Philip Bellingham, Fenella Sleigh, Brian Gouws

HELPING THROUGH YOUR WILL

Your Will can be a convenient vehicle for making a charitable gift of a lasting value. Please consider MND Association as a living memorial for a loved one. Many people support the work of the MND Association of South Africa through bequests from their Estates.

**We welcome your ideas – THUMBS UP is your voice –
So if you would like to Contribute to the next issue – Please write to us !**

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