

# Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



*Tony Katzew (left) and Colin Danin at their "Reunion"  
(Read their stories inside)*

**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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**NATIONAL CHAIRPERSON**  
Dr. Peter Vurgarellis

**VICE CHAIRPERSON**  
Vivien O'Cuinneagain

**TREASURER**  
Enid Katz

**SECRETARY**  
Rina Myburgh

**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

Having served as Chairman of the Motor Neurone Disease Association of SA for 4 years, Dr Peter Vurgarellis has decided to step down from this position at the end of September 2008. With his numerous other commitments he feels that he is unable to give the MNDA the time and attention it deserves. We thank Peter for his past input and guidance and wish him well in all his other endeavours.

We have pleasure in advising that Dr Franclo Henning {MBChB (Stell), FC Neurol (SA)} has agreed to take up the position of Chairman from October. Dr Henning was born in Worcester, attended school at Paarl and Wellington in the Western Cape and studied at the University of Stellenbosch, specialising in neurology. He did a clinical fellowship in neuromuscular medicine at the Rudolph Magnus Institute, University of Utrecht, Netherlands, one of the largest MND referral centres in Europe, and is currently a consultant neurologist at Tygerberg Hospital, Cape Town.

We welcome Franclo on board and look forward to working with him.

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**IT'S THAT TIME AGAIN !**

**Our Order Form for MNDA Christmas Cards is enclosed.**

***Please support your Association !***  
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**Banking Details:**

Motor Neurone Disease Association of SA or MNDA of SA  
 Account No 27 062 913 0 - Standard Bank - Rondebosch Branch Code 025009  
 (Swift : SBZAZAJJ 02500911)

## DONATIONS

PM Snyman (Monthly), R Hollings. P & R Thorburn, JE Dillon, AA Forder, SL Harris, NG Kerk Dannhauser (Janie Zaal), A Gilbert, Keith and Marion Barrett,

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*In memory of Kenny Rhode* : Members of Volkskerk van Afrika

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*In memory of Frank Haarhof*:

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*In memory of Ken Downhams*:

Hull, Alpine Automation, Stefan Muster, Mitek Industries, Jordan (Honeydew), S Store Hartebeespoort, Kim Heller, Lorna Slawitsch  
*The Parker family in memory of Halima Parker*

We also received donations where we were unable to identify the donors or on whose behalf it was intended. We would nevertheless like to thank each and every one for their kind and generous support.

*Nicky Elridge, who lives in London, and is a daughter of the late Michael Swanson (MND patient) held a coffee morning and sent us the following e-mail:*

In honour of my beloved dad, Michael Swanson, who died on 23 November 2006 after a courageous battle against motor neurone disease, I held a coffee morning at my home in London on Friday 29 February 2008 to raise funds for the Motor Neurone Disease Association of South Africa. It would have been my dad's 63rd birthday on 2nd March so my coffee morning was held in his memory and will hopefully become an annual charity fundraiser for the MNDA.

At the coffee morning, people made donations to the MNDA in exchange for a cuppa and a croissant! I also took orders for the greeting cards I sell as a Phoenix trader here in the UK and all the profits from these sales have gone into the fund. The total amount raised from the coffee morning and the sale of the cards is 645 pounds! We all hope that these funds will go some way to helping others currently afflicted with this dreadful illness in South Africa. They were made by people who knew and loved my dad !

*We could learn a lot from crayons:*

*Some are sharp, some are pretty, some are dull, some have weird names,*

*And all are different colours .....but they all exist very nicely in the same box !*

**“THUMBS UP ! NO END TO CARING”**

Mandy Snyman, a patient from Port Elizabeth, who was diagnosed with MND in 1998 and is now wheelchair bound, arranged (and directed !) a spectacular charity benefit concert with Algoa FM in association with Magnetic Storm. This one-night-only event featured the finest names in the entertainment industry amongst who were Ian

von Memerty of "Strictly Come Dancing" fame and South Africa's musical theatre Diva Divine, and patron of MND, Aviva Pelham.

The event was held in aid of the Motor Neurone Disease Association and St Francis Hospice and took place at the Port Elizabeth Opera House on Friday 1 August – a day that was also Mandy's birthday !

A big round of applause must go to Mandy in particular, as well as all the wonderful people who assisted her, and those who committed themselves to make this event the great success it was !

MND of SA and St Francis Hospice each received a sum of R23,792 - MANY THANKS !

A thank you also to all our MND patients and their carers in that area who made the special effort to attend this grand occasion !

A DVD of the show is available at R100 per copy from Mandy's sister, Sheryl. You can reach her on 082 894 4524 to order your copy.

## MAIL BAG

*We have received some interesting input from patients and their spouses and we would like to share it with all of you.*

**Ingrid Danin**, wife of MND Patient Colin Danin of Johannesburg, writes:

2nd July, 2008 Today is our 41st Anniversary -

My husband Colin Danin was born on the 16th August, 1942. Colin has Motor Neurone Disease which was diagnosed in 2000. His muscles were twitching and the fasciculations were flickering all over his body. He was already experiencing weakness in his legs, arms and hands. He was then sent to the head of neurology, Professor Kees van der Meyden in Pretoria who was soon to retire. Colin knew him in high school, as he too was a chess player. After many tests he then sent us to Dr. Malcolm Baker at the University of Pretoria, who had trained and worked at the Mayo Clinic, USA. His diagnosis confirmed that Colin had MND. We still speak to Dr. Baker a few times a year and find him to be the most empathic, patient and brilliant man.

In America they call this disease ALS (Amyotrophic Lateral Sclerosis) or Lou Gehrig's Disease - Lou Gehrig was a famous baseball player. In the UK, Australia and SA it's known as MND. Every aspect of Motor Neurone Disease was investigated to find out which form of MND Colin has, which meant that he had to undergo a lumbar puncture, 17 sessions of dialysis, blood tests and genetic testing. His form of MND is not genetic and is unfortunately fast progressing, though this has been slowed down, I believe, due to Colin being on a ventilator. He has outlived his original prognosis which was 3 to 5 years. We are happy to say that Colin has just celebrated his 8th anniversary.

We then connected with the Motor Neurone Disease Association (MND) of South Africa and in America, who sent us information and were very helpful in directing us. MND is an International Alliance who updates us regularly with results of research that has been done. We have studied the MND booklets, reports from symposiums held all over the world and all your newsletters, which have been most informative. We have also read articles written by Doctors in Holland, Sydney and Melbourne, where international symposiums, on MND, were held. I have spoken to Doctors in San Diego, USA and Italy whose main research is with stem cells. The cause of MND is unknown, but it is a progressive disease that affects the

nerve cells in the spinal cord, due to lack of protein. They have no idea how to put the protein back into the spine. Stem cell research will probably one day contribute towards a cure. We read about the Euan MacDonald Centre for research in Edinburgh with interest and are thankful that generous people like the MacDonalds exist. In the meantime Colin's progressive weakness has resulted in paraplegia, almost total immobility and respiratory failure. I bought Dr. John Bach's book, "Guide to the Evaluation and Management of Neuromuscular Disease", which is hands on, informative and has helped us over the years.

Before this disease, Colin hadn't seen a Doctor in over 30 years. We went to a homeopath too, to see if anything could be done through alternative medicine. One clutches at straws. Colin had to describe himself to the homeopath and I quote: "I am an extrovert, sociable and cheerful. I have a placid disposition, can easily relax, am content and calm within myself. I am optimistic, often sarcastic and use my sense of humour to cheer up others. I am easy going, articulate, independent (which our kids call controlling) and take an interest in family, friends and world affairs."

Colin still has many friends, some of whom he used to play tennis and poker with, others have been our social friends, some from over 40 years ago. He has a profound effect on people and we have rekindled relationships with cousins and friends we hadn't seen since school days. We have not dissociated from family or friends, as you can hear. They feel comfortable in our presence due to our acceptance of Colin's condition. In fact we have grown closer to and have cultivated an incredible network of treasured relationships. Everyone loves Colin due to his ability to connect favourably with people, to be sensitive to their issues, to tell jokes, to listen with interest and due to his incredible memory, is interesting himself. He has to lie down with the aid of a ventilator for a few hours before people visit, so he has sufficient lung capacity and a stronger voice in order to entertain them. Unfortunately in the past few months his voice has become a whisper and his breath is failing him for more than 20 hours a day. His positive attitude, acceptance and appreciation of the quality of life he still has, is amazing. He is philosophical in the face of adversity and is not bitter or resentful. He doesn't blame God for the bad things that happen. He hasn't taken his illness "lying down" and with the help of our sons and daughter-in-law, we were able to source a home ventilator / BiPAP machine and a voice amplifier which have

added to Colin's quality of life. Our overseas families constantly send us satin sheets which allow us to turn Colin more easily and special bed-bath wipes. I have a laptop computer which enables Colin to connect to our daughter, son-in-law and grandchildren in England and to see them on Skype. Just a few months ago we also investigated "The Grid 2", which Andy Gilbert spoke about in the May 2008 "Thumbs Up". Colin has been practicing and managing quite well to move the cursor with his head, which enables him to communicate more freely. The idea is that once his voice goes completely he will not be trapped in his body, he will still be able to tell us what he wants, once again ensuring a more rewarding lifestyle. We connect with Sister Liz Ketch from MND Johannesburg, Dr. Sally Garb from Hospice, our local Rabbi and Maureen McLeman, Colin's physiotherapist who comes to our house every second Friday. We would not cope on a daily basis without our Carers, Thuli and Liz. (I am enclosing a photo of them with Colin). To all of them we say a heartfelt thank you.

The other day Colin, lying on his bed with his mask on, asked his physio: "Are my test results back?"

She whipped down his pants and felt between his legs.

Colin responded: "That's really nice, but you didn't answer my question." I asked you if my test results were back.

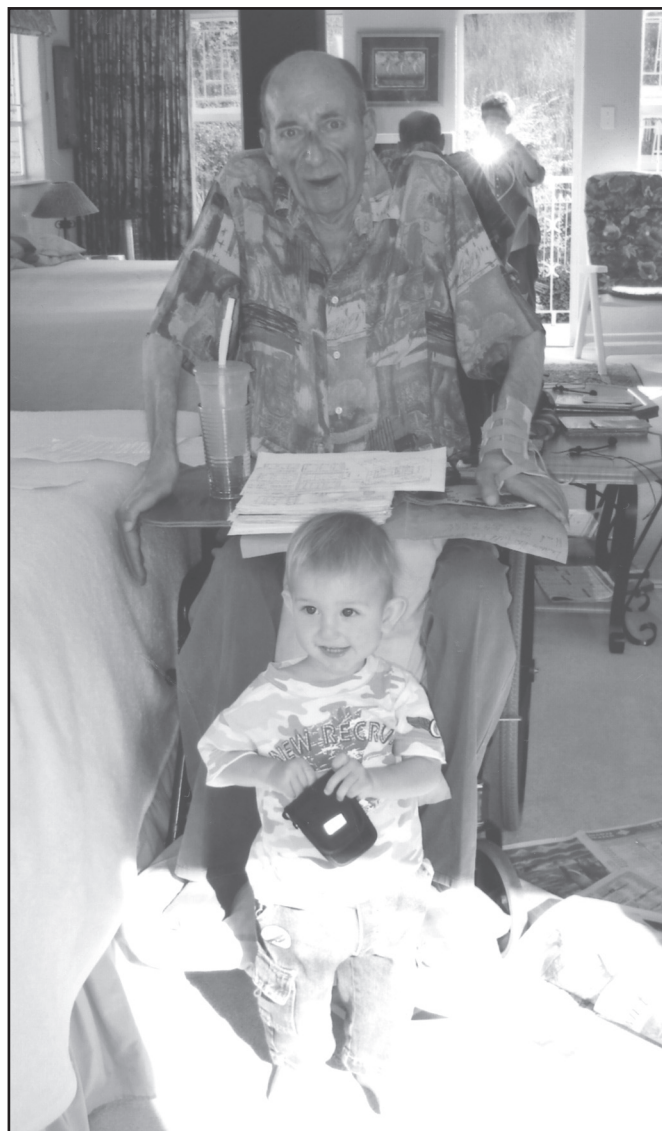
The physio was shocked and said, your voice was muffled and I thought you asked if your testicles were black?" (Joke!!)

Colin and I lived in Kensington, Johannesburg, in the same street, throughout our childhood but never knew each other. We got married in 1967 and for the past 41 years Colin has been my pillar of strength. He communicates, empathises, understands and encourages. He is always available and basks in my professional success. Part of my greater purpose in becoming a social worker must have been in preparation for looking after Colin through this illness. What we loved the most was dancing, eating out, being active and the theatre. Colin's passion was judo and he went to the Maccabi Games in Israel in 1965, representing South Africa. His talent is writing poetry. His love, which has kept him going these past few years, is designing furniture. His Carer and I are still being instructed, step-by-step, how to continue drawing his designs. Perhaps this will be one of the legacies that Colin will leave behind.

He has always been an involved father but since our 5 grandchildren have been born, they have only known their "Grandpa" to be in a wheelchair and looking like an alien with his mask on. I am sending a photo of our 18 month old grandson, Josh, sitting at Colin's feet (print it if you wish). I am also sending a photo of Colin and Tony Katzew, an MND patient living at Hospice, who recently visited us. He and his brother from Australia hired a "London Taxi" which accommodated Tony's wheelchair, with him sitting in it. To meet with visitors downstairs, in this instance Tony, Colin came down into the garden, on his "chariot", from our bedroom on the second level. When Colin was manufacturing furniture he converted a forklift into "a lift" which has achieved its purpose, except when it's raining. Both Colin and Tony are totally dependent and immobile but amazingly grateful and undemanding. Colin still enjoys hearing

and telling a good joke and what gets him through each day is his sense of humour and watching TV. His request for his 66th birthday, on the 16th of August, is that we arrange a "lap dancer" to entertain him !!!!! Colin tries to lighten everything up, but as this disease progresses the "light" is beginning to fade. There is comfort in knowing that we are not fighting this alone and we are grateful for all the support and care of everyone around us.

In Love and Light, Ingrid



*Colin and his grandson Josh*

**REUNION AFTER FOUR YEARS** (See photo on front page)  
My name is Tony Katzew, and I live at the Witwatersrand Hospice. On the 14th May I received a totally unexpected visitor. My visitor was none other than Ingrid Danin, whom I had last seen four years ago. She said to me that for the last three months, almost every day she had said to herself, "I must visit Tony Katzew". Ingrid's husband, Colin, is an eight-year veteran of Motor Neurone Disease. He has an inventive mind, it is a pleasure to be in his company, and he has a great sense of humour. Being a six-year veteran, and seeing Colin's fighting spirit, I am filled with admiration for him.



On Tuesday, 17th June, the Johannesburg Star newspaper printed an article on Hospice and on me, and that was the inspiration for Ingrid to come and see me again on Monday, 23rd June. During that visit, I made a promise that I would take a London taxicab and visit Colin at their home. Ingrid welcomed this undertaking, and when I told my brother Michael, who was on a six-day visit from Melbourne, Australia, he suggested that we go the very next day. Ingrid confirmed that Tuesday, 24th, was suitable, and we arrived at their house at midday.

It was great seeing Colin again, and although he had developed breathing difficulties, his indomitable spirit shone through like a ray of sunshine. Ingrid was a superb hostess, and the hour literally flew by. For me it was an exhilarating hour, talking and listening to Colin, and we undertook to repeat this exercise when Michael next visits during November 2008.

An important thing I must point out to you, the reader, is that the words "why", "if", and "if only", have never been, nor will be, part of our vocabulary.

"Thank you!", to the Danin's, for your great hospitality, and au revoir until November.

**Prof Andy Gilbert** (patient) and his wife Yvonne (below) recently attended the wedding of their son in New York, and they share the trip with us:

After a very difficult 2 months, Andrew had his 3rd PEG put in 10 days before we were due to fly to New York. We were both very anxious about travelling so soon after the operation. PEG feeding in public was one of our concerns, as was his strength and any repeat problems with the PEG. However, we were determined to get to our son's wedding and so with all the normal caution thrown to the wind, we set off on our journey. First from East London to Joburg and then 17 hours to JFK Kennedy Airport. We soon found that travelling as assisted passengers was really easy as we waited in no queues at all, and once on the aeroplane there is literally nothing else to do, so one relaxes and just lets time pass. We had taken 6 x 200 ml boxes of Fresubin on the plane with us, (no-one requested to see our Doctor's letter saying that this was prescription food). This was very easy to put down the PEG, no mixing, or lumps only a syringe that needed rinsing. Only for 2 meals on the return journey, were we given the 'Liquid diet' requested by our travel agent. It seemed noone had ever heard of such a thing. A whisky and soda also went down the PEG which definitely helped us to relax. A sarong helped us to maintain some privacy, but generally we found that most people looked the other way.

Being there to share this very special day with our son and new daughter-in-law was just wonderful. The weather was hot and humid and so 2 beers went down the PEG at the wedding, the pity is that we couldn't get the 'fillet mignon' and fresh asparagus down! We found



*Prof Andy Gilbert (patient) and his wife Yvonne*

that there were times when Andrew would need/prefer to go and feed privately in a bedroom, but at other times we sat anonymously under the trees on Boston Common and in Harvard Yard and felt that was quite appropriate to rehydrate or have a feed. The holiday was a calm and simple one of spending time with important people and not trying to see or do a lot of tourist things. We did find though that those museums that we went to and one of the big shops, had electric scooters for client's use. That made it great for Andrew, allowing him to have some independence to see/read/enjoy what HE wanted not just what the wheelchair pusher was interested in.



*Magre van Deventer of Uitenhage*

**Magre van Deventer** of Uitenhage, in his new chair and keeping him company (although rather lazily !) is one of his pet Labradors, Sasha. Magre sent us the "Ten Commandments for the Management of ALS" which reads as follows:

1. "Leave no stone unturned"  
The diagnosis must be made by experts and confirmed independently, since the diagnosis is entirely clinical and objective laboratory testing is lacking. The Amyotrophic Lateral Sclerosis (ALS) type of MND is usually fatal and each patient deserves expert confirmation.
2. "Hope springs eternal"  
Even if no other diagnosis seems likely, hope of a less serious outcome must be preserved. Do not crush all hope.
3. "This is a family disease"  
The whole family should be involved as soon as the diagnosis is confirmed, because much of the burden will be on them as well as on the actual sufferer. Encourage the family to be present at all examinations, tests research procedures, etc
4. "Early intervention to ameliorate symptoms"  
Many MND symptoms can be reduced by the use of a variety of simple treatments, which should be utilised to ease the effects of progression. To do otherwise is a disservice and indignity. Avoid superimposing manageable problems on an already difficult situation.  
Should worse come to worse and a terminal state be reached, the generous use of powerful narcotics has absolutely no risk of

addition and guarantees comfort in the last days. "Go out in good spirit with flags flying and whistle wet".

5. "You are not abandoned and alone"  
There are world-class researchers devoting themselves to solving this disease – the sufferer is not alone and abandoned. Support is available.
6. "Be it ever so humble, there is no place like home"  
In most circumstances home care is best! Brief admissions in the hospital for more Significant treatments may be appropriate later in the illness. However, again, encourage family attendance.
7. "An informed patient is the most effective patient"  
Keeping everyone as fully informed as possible about what may be next is to respect their intelligence and integrity. Their decision about what is best for them should always be respected. The difficult decisions about life support or assistance should be discussed openly early, without prejudice and be made by the patient before they are needed.  
Refusal by the patient to participate in research or life support, or a wish to self-administer unlikely treatments or alternative health methods, such as vitamins, acupuncture, meditation, etc. should not be derided or decrease attention by the attendant health professionals.
8. "The patient is in charge"  
Never forget that the patient is in charge throughout the illness, Physicians, nurses, physical therapists and other health care attendants are serving only to aid the patient and to help the family manage as well as possible.
9. "Maintain family finances and the home"  
Equal attention must be given to the family finances and maintenance of the home, Especially when the MND victim has been the wage earner or the principal in the family.
10. "Maintain patient and family morale"  
Maintain patient and family morale with respite and support during the long haul. This is perhaps the overriding, and final consideration in MND management. Everything, including medical and nursing care, invariably goes from bad to worse when morale is low and likewise good morale can compensate for many seemingly dire problems.

**Young Carers have hearts of gold** (taken from Summer 2008 Edition of Thumbprint):

**Miranda Wallace** (21) of Gloucestershire writes:

It started in 1998 when my mum, then 34, was diagnosed with MND after she had my little sister.

It only took around 10 to 12 months before my mum couldn't do all the usual things – and that's where I came in!

I was only 12 when my mum was diagnosed so I wasn't really aware of all the facts. My dad was still with us but not around as much as he should have been so it was up to me to look after and care for my one-year-old sister and 7 year old brother.

As I was still at school, a carer would come in during the day and then I would take over when I got home.

I would start by taking off my uniform and also helping my brother with his. Then I would cook dinner for us all and help my mum by

feeding her dinner to her. I would then wash and dress my siblings and get them into bed. After that I would help my mum with her hygiene and wash and dress her ready for bed too.

While my mum was happy, clean and watching TV last thing at night, I would do the housework, washing up, washing clothes, vacuuming, etc. Daily chores were a challenge in my house! So when my day was through I felt happy that everyone else was as happy as they could be.

I got involved in a group called Young Carers. I loved being in that category as I was so proud. Sadly my mum passed away in March 2000. I am now a mummy to two beautiful children and I'm glad I enjoyed the experience caring for my mum until the very end.

So just a little message for all the young carers – it's not a chore you're doing, it's because you have a heart of gold.

*A mother who was a physician was taking her 4 year old daughter to pre-school.*

*She had left her stethoscope on the car seat and her little daughter picked it up and began playing with it. Be still my heart, the mother thought, my daughter wants to follow in my footsteps!*

*Then the child spoke into the instrument:*

*“Welcome to McDonald's. May I take your order ?”*

## HINTS

### Sharing the Diagnosis

Some of us like to be very direct and open and are happy to share quite personal information in life; while others prefer to keep things to ourselves.

This makes it impossible to create a 'how to' guide to sharing a diagnosis of MND, as what may feel right for one person may be wrong for another.

Experience shows that people often want to protect those they care about and so may try to keep their diagnosis to themselves, meanwhile those who care about them know something is wrong, but don't know what. This can lead to additional stress and worry for everyone.

This is particularly the case when children are involved. No matter what age they are children will sense all is not well. Not knowing what is going on or feeling excluded is often worse than knowing the facts.

- Think about how much you want to share
- Use a communication method that you are comfortable with, maybe you would prefer to write rather than speak. You could use an advocate to speak for you
- If someone speaks on your behalf take time to plan with them what you do or don't want them to share
- Tell them what you want to do and how you want to be treated
- Try to be prepared for people's reactions, they can be very varied. Sometimes people may not know what to say or do, so may avoid further contact, other may feel they want to do everything for you

**From Peter Marx**, husband of MND patient Marion Marx of Somerset West:

### Marion's laser used as a head pointer

My wife Marion has a form of Motor Neurone Disease. MND patients suffer from varying disabilities as the disease progresses. In Marion's case she is unable to speak or move any of her limbs or fingers or toes. She is still able to move her head fairly well. There are a variety of aids that assist a patient in communicating such as small computerised typing devices that have screens that both the patient and "listener" can read whilst the patient types. Boards with letters or pictures that the patients can point at to make themselves understood are also a useful aid. However, most of these aids require some manual input to be of any use. For this reason all the aids that require any hand, finger, leg or foot movement on the part of the user were of no use in Marion's case.

Marion is a member of the Somerset West MND group very ably run by Vivien O'Cuinneagain. When Vivien realised that Marion was getting to the stage where her speech was really becoming very difficult for the listener to comprehend, she introduced us to a laser which could be harnessed to the head. Vivien made the harness herself and it consists of a broad elastic band which has Velcro sewn onto it. The band can be made into a circular ring by means of the Velcro and the size of the ring can thus be varied to fit variable sizes of heads. Sewn onto the elastic band is a loop through which a pencil shaped laser can be attached. The circular elastic band can be put over the head just above the ears with the laser positioned at one of the temples and the beam pointing forwards. With the laser strapped to her head Marion is able to move her head so that the laser beam points at a letter board. We place the laser on her right temple but one could use the left temple just as well.

The original laser was a very cheap one that was purchased at a toy store for children to play with. It proved to be completely inadequate as the beam was very weak and could only be thrown a short distance. In addition the batteries which were the size of the type fitted to watches or hearing aids went flat in a very short space of time. We purchased a good laser of the type lecturer's use when pointing out things on a blackboard. They cost in the region of R200 each. The one we purchased uses two AAA batteries. We use rechargeable ones for convenience. It has a push button switch. When pressing the button the laser comes on and when it is released it goes off as the button is spring loaded. The laser is very bright and covers a far greater distance than one needs in practice. The batteries last for a long time. Even when Marion jabbars a great deal we still have good use for at least two days. I have left the laser on overnight in error on occasion and the next morning it was still working fairly brightly.

She is thus able to spell out words on a letter board by pointing the beam at the various letters on the board. She was able to "talk" to her six year old grandson on one of his visits from the UK. He actually enjoyed communicating with Marion in this fashion, and hopefully his spelling improved as a result! The letter boards we use are set out like the keys on a computer keyboard. However it is a matter of preference and one could for example arrange the letters in three

rows in alphabetical order if the user happens to be someone who has never typed before. Around the edge one can put key words frequently used to avoid having to spell everything out. As an example our letter board has the following key words amongst others: - no, yes, toilet, drink, TV, itch, wipe etc. Our board also has a simple diagram of a stick woman on it. If Marion has an itch for example on her left arm, she would point at the word itch and then at the left arm of the stick woman. The original of the letter board was designed and made up by Marion's brother. It is 55cm wide x 40cm high and made in such a way that it stands free in a vertical position. When having long conversations we use this board. We photographed the board and had it printed onto a few printer paper sheets and then had the sheets laminated. These are placed at strategic points in the house for convenience sake. It is easier rather than carting the big board around every time Marion wishes to say something.

In order to have the laser on without having to depress the switch continuously we used a washing peg clipped over the switch to depress it. This was effective but the source of curious staring when people saw Marion being pushed around in public places with a contraption on her head! It was also a bit of a fiddle positioning the washing peg over the switch so that it did not jump off the pencil shaped laser. After a few months I took the laser to an engineering firm. They drilled a small hole into the laser where the switch was, and removed the press button switch. Two fine wires were soldered to the original poles of the switch and a small ON/OFF toggle switch attached to the end of the wires. The wires and toggle switch are taped to the laser with ordinary insulation tape. The final product works like a charm and we have had it for a few years in constant use without any problems.

was there .... After a year or two, I spent an hour walking between the bars.

Furthermore, physiotherapy helped me a great deal (especially to stretch my muscles, to prevent it from shortening). At first I had physiotherapy 3 times a week, for an hour, but soon I was cut down to two times (as I "came loose", after a while). At the moment I only go for 1 hour's "stretching" a week. But I try to not miss out on walking ....

I want to encourage all MND-sufferers to do as much exercise as possible, while they still can, because you really lose mobility quickly ! I am talking out of experience. Although you might be having pain (sometimes lots of it), keep moving as much as you can, and stay active!

**Condolences to the family and friends of:**

Francois van der Linde, Liz van der Merwe, Hayley Cleland, Deon Mynhardt, Spratt Davis, Abraham Dreyer, Frank Haarhof, Salomie Dreyer, John Raftesath, Kenny Rhode, Solomon Nqwenya, Heb Paquay, Jaap Momberg, Ron Morris, Kenneth Downhams, Ferdinand Dorfling, Dorothy Obertelli, Sheila Anderton, Robin Poole, Rose Willemse

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

***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.*

**Patient Ben Viljoen of Queenswood, Pretoria, gives this advice:**  
 Exercise  
 This is a very important secret in my wellbeing. The slogan "Use it, or lose it" applies .....

I try to walk between the parallel bars at least 3 times a week. My brother who is a medical doctor, urged me to spend at least 5 minutes at the parallel bars "for a start", when I just came to the Frail Care Home. He told me to just stand up and sit down again, to exercise in the beginning. But just to be there for at least 5 minutes. Soon I was spending a quarter of an hour there, just getting up and down. And I then ventured to start walking. At first it went along with much pain, and I could only walk to and fro for a maximum of 3 times. But I

**MOTOR NEURONE DISEASE ASSOCIATION of South Africa**

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