

# Thumbs UP

**MNDALS**  
Association of South Africa

The Newsletter of the  
Motor Neurone Disease /  
Amyotrophic Lateral Sclerosis  
Association of South Africa

June 2015



*THE CORNFLOWER  
GLOBAL AWARENESS DAY: 21 JUNE*

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."

MNDA of South Africa is a member of the International Alliance

**PATRON**  
Aviva Pelham (M. Mus.)

**NATIONAL CHAIRPERSON**  
Dr. Franco Henning

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**SECRETARY**  
Rina Myburgh

#### ACKNOWLEDGEMENTS

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



*Life is a play.  
It's not its length, but its performance that counts*

### DONATIONS

A MNDA SMS LINE HAS BEEN ESTABLISHED FOR  
DONATIONS TO THE ASSOCIATION !

**SMS "MNDA" TO 42646**

(Cost R30) Please advise family, friends and acquaintances –  
anyone with a cell phone – and that is just about everyone !

### ***We would like to thank:***

David Cuthbert, Jenni Newman Public Relations, Diesel Electric Services, Masonic Bowling Association, Unger family, Mazzucchelli family, Sue Lane, Rosalynd Els, Angelos Yiannou, Bev Vermeulen, Kirsten Smith, for donations received in lieu of birthday gifts, in memory of loved ones, or just as a kind gesture.

## FUNDRAISING



Sandy Bailey and members of 'The Thursday Club', arranged a luncheon at Buitenverwachting in Constantia to raise funds for MNDA of SA. This was at a suggestion from their friend, Philippa Jolly, who recently lost her brother to MND. Various great prizes such as Golf Club Vouchers, Spa Treatments & Massages, Dinners for Two, and a lot more as well as a signed copy of "The Real Meal Revolution" by Prof Tim Noaks, were sponsored and the popular and well-known Clem Sunter, was guest speaker. It was a glorious Autumn day and the weather certainly could have contributed to the mood, as a generous R5,255 was raised. So a big thank you to each and everyone involved in making this happen. Philippa and Sandy visited our office in Cape Town to personally hand over the donation and by the sounds of things, they are thinking of making this an annual event.

## MAILBOX

*Nicky Fuller of Garden View, Johannesburg, writes:*

My husband, Bob, has had MND for almost 9 years. We together head up the Student Affairs Department at The King's School, Linbro Park. When the new Grade 1 classes start the year, they bring them to meet Bob who thankfully is still able to come to work every day.

I try to explain to them what MNDS is, what his restrictions are, and show them how he uses his computer with his eyes. The next day a few of them stood watching the caregiver and I as we moved Bob from the car into his chair. One little boy, Victor, was so focused he was barely blinking. This was the conversation he was having with the others: "Do you know, Mr Fuller can't walk, he can't talk, he can't eat and he can't speak. Why doesn't she take him to the doctor?"

*Dup Herselman of Melmoth sent us an article which featured in The Mid South Coast Rising Sun (April 14-20: "Woman with motor neurone disease pampered in Scottburgh". (We quote an extract thereof):*

As many of the Scottburgh area's Easter visitors wended their way homewards, a special one arrived for a two day visit to Scottburgh before moving down to the Margate area. Short although her time in Scottburgh was, it was very special to Rita Herselman of Melmoth – a wife and mother of two, who has motor neurone disease.

Assisted by her two dedicated friends, Bekkie Conroy and Anita Gill and many supporters, Rita enjoyed a holiday at the sea that she will long remember, however short it was. The Rising Sun was privileged to accompany her on two of her ventures – to the hairdresser and onto Scottburgh main beach into the sea itself and was able to marvel at her wonderful spirit and positivity.

Rita was diagnosed as having MND in August 2014 after about 4 years as the disease gradually invaded her space. She underwent extensive tests before diagnosis was confirmed, part of the problem being that two successive hip replacements which malfunctioned helped to distract attention from her MND symptoms.

Spreading awareness is a key need and Rita hopes to spread the word. She praises God for helping her, including through the gift of drawing. She has already been offered R4,000 for one picture and encouragement with others.

If you want to contact Rita, she can be reached on 076 828 6721.

**Kasturi** (KZN Support Group) sent us this photo of Jasmine Moodley & Gary Stewart, two of a group of patients and carers at a screening of the Oscar-winning movie, (story of Peter Hawking): “The Theory of Everything” for which they were given free tickets by VIP Lounge.



### ***BEDTIME STORY ...***

*The doors are all locked the security gates too  
 Burglar-barred windows make it look like a zoo  
 The alarms are all activated and the cars are pulled in  
 The electric fence is buzzing, the motion beams glow dim  
 The Rotties are snoring in their baskets in the hall  
 So they can't be poisoned over the wall.  
 The gun's out the safe and under the bed  
 Our prayers (to survive through the night) have been said ....  
 So, Nighty-night, we hope you'll sleep tight,  
 We'll leave it to Eskom to switch off the light !!*

### A request for Greeting Cards

As you may be aware, we like to send our patients a card on their birthday and to keep costs down we make use of recycled cards. We have a request : should any of our readers have cards (just the front – with a picture image) they could let us have instead of throwing them away or any other pictures / old post cards which would be suitable for ladies and/or gents, please forward them to us at MNDA of SA, PO Box 789, Howard Place 7450. We need to build up our “stocks”!

## HINTS & TIPS

Where there's a wheel there's a way - An overseas member, Mick Dart, advised that after an increasing battle trying to use a knife in his steadily weakening right hand, he found that a pizza wheel is the answer ! He suggests you try it !

### Wheelchair Transfer Seat



An easier way to move a person from/to a wheelchair and to/from a car or to facilitate other moves or changes in places/positions. This handy transfer seat is available from NFAYO Products, Cell 073 459 3646 - Currently priced at R650 and a courier delivery service could be arranged for R99.

Food is one of the pleasures of life, but when swallowing becomes difficult, the natural reaction is to eat and drink less than before, and to avoid the foods which cause problems. Over a period of time, this leads to loss of weight and feeling tired – so what can you do ?

**There is no special diet for MND/ALS.** The best current advice is to eat a varied and balanced diet, taking care to include enough fibre and liquid and foods that are particular favourites.

You may find it easier to eat smaller meals more frequently rather than regular meal times.

If you miss a meal, eat as soon as you feel hungry again.

Replace a “lost” meal with a food supplement such as Ensure or add this to your favourite food, enriching foods and drinks to boost their nutritional value.

Altering the consistency of foods to make them easier to swallow, ie. Liquidizing.

Try to relax in a quiet atmosphere when eating and concentrate on the swallow. Do not hurry. How you sit when eating is important, the recommended position is to sit upright on a firm chair with your head well supported.

**Possible foods to avoid are:**

- Mixed textures and liquids with bits in, such as minestrone soup
- Foods that need a lot of chewing, such as fresh bread, vegetable skins
- Stringy food, such as bacon, green beans
- Coarse hard food, such as nuts, hard toast
- Sharp or spicy foods can increase the flow of saliva for some while others find that the strong stimulation of these kinds of food aids swallowing

The foods that are difficult to swallow vary widely from person to person - some people cannot eat toast, others can, but not jelly. In general liquids cause more difficulty than solids, and food of a semi-solid consistency (like porridge) is the easiest to manage. Experiment to see what suits your needs best.

**And then there is:**

**PERCUTANEOUS ENDOSCOPIC GASTROSTOMY (PEG for Short)**

When swallowing becomes very difficult, or you are taking longer than forty-five minutes to finish a meal, feel tired thereafter, have a lot of weight loss, difficulty with breathing or experience choking and coughing, then maybe you could consider an alternative way of being fed. This is known as PEG for short - a short easy procedure that inserts a small tube into your abdomen and all your nutritional requirements can be administered via this tube.

Several questions come to mind which you would like answered before deciding whether to have this done.

**Questions and Answers –**

*What is a PEG?*

A PEG is a small tube which is inserted directly into the stomach through the abdominal wall.

*How can a PEG help?*

Eating and drinking can become uncomfortable and difficult and consequently mealtimes may prove to be stressful. Problems with swallowing often results in inadequate food and fluid intake, so help with feeding is then needed to build up energy levels.

*What are the benefits to me?*

A PEG tube can remove the anxiety which often accompanies meals and allows you to obtain all the required nutrition from prepared liquid feed.

*Will it help my Motor Neurone Disease?*

No. Your disease will continue to progress irrespective of having the tube placed, but if you are having problems in the early stage of the disease, it may help with energy levels and make you feel less tired.

*Will I gain weight?*

This will depend on how many calories you can tolerate without causing stress on the diaphragm. Some people do gain a little weight, but this will be monitored by a dietician or professional.

*Will I be able to eat by mouth?*

Some people do still manage to eat and drink a little by mouth afterwards. This will depend on you and whether it is safe for you to do so.

*How will I take medication?*

Medication will be prescribed in liquid form wherever possible. Otherwise it can be crushed and administered via the tube. A professional can show you how to do this.

*Will my bowels be affected?*

Many people with Motor Neurone Disease have trouble with their bowels due to poor intake of fluid and fibre. Remember the pelvic floor muscles are probably weak and the pushing sensation gone. Sometimes by having tube feeds, and the increase in fluid it can become a little easier. Many times laxatives have still to be used.

*Will I be able to bath or shower?*

For the first little while until the wound has healed, it is advisable not to. After that, as long as the tube is closed, then yes.

*When should I have the tube fitted?*

This decision should be discussed with your family, doctor and therapist if you have one. Consider PEG before severe weight loss and too much difficulty with breathing. Consideration should also be given to the changes it may have on your lifestyle.

Whatever you decide **it is your decision** and no one should push you into a corner to have a PEG placed. Many people decide that it is not the correct route for them. Others decide very early in the disease and have the procedure done long before difficulties arise. The **decision is yours alone** and should be respected by all who look after you.



### Condolences to Family and Friends of:

Carl van Lierop (9/2), Stephen Carmichael (19/2), Pierre Viviers (6/3), Roy van der Westhuizen (20/3), Alan Michel (26/3), Gordon Oliver (1/4), Jacques Rossouw (1/4), Karin Ashdown (12/4), Paul van Zijl (16/4), Eleanor Purdon (27/4), Louise Eijbers (4/5), Phillip van Rensburg (16/5), Dhanpal Pillay (16/5), Lettie Slabbert (18/5),

**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.*

### MOTOR NEURONE DISEASE / ALS ASSOCIATION OF SA

Cape Town Office  
P.O.Box 789, HOWARD PLACE, 7450,  
TEL: (021) 531-6130  
FAX: (021) 531-6131  
E-mail: mndaofsa@global.co.za

Gauteng  
CELL: 082-878-3716

Port Elizabeth Area  
CELL: 072-326-4477

Durban/KZN  
CELL: 083-777-2029