

Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



May 2009

Southern Cape Support Group

*From left: Dave & Jozanne (MND), Joseph & Jacques (MND), Derrick & Wilna (MND),
Linza & Francouis (MND) and Rita & Leon (MND)
Wilna sadly passed away on 2 March 2009 (Monday)*

**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

PATRON
Aviva Pelham (M. Mus.)

NATIONAL CHAIRPERSON
Dr. Franco Henning

VICE CHAIRPERSON
Vivien O’Cuiinneagain

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

TWO MNDA FUNDRAISERS !!

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*Thursday 16 July 2009 @ 20h00 at
Theatre on the Bay, Camps Bay
Come and see ALAN COMMITTIE
in his 8th One-Man Show
BIGGER ! BETTER !! and FASTER !!!*

***Tickets at R150 or R125 (upstairs) available from
Roxy on 082 468 8980
Aviva on 083 378 0914***

*You will be welcomed with a glass of wine on arrival and some lucky ticket holders
will receive a gift !*

Please support us – get your tickets early !!

DINNER

*on Saturday 1 August 2009 @ 20h00 at
THE FOODBARN
270 Main Road, Noordhoek*

*A theme evening where the food would complement the music !
Aviva Pelham (our Patron) will be the star of the evening !*

Tickets : R600 per person

*Get your family and friends to join in and make up a table of 8
(10 tables can be accommodated)*

For Bookings please phone 021 789 1390

From the Office

Membership fees of R100 were due from 1 April. We thank those who have already paid (and for the extra's) and this serves as a reminder to all our other members/readers.

Should you send a cheque, please ensure that all details are correct as we would not want the bank to return cheques which would lead to extra bank charges for us all !

Banking Details: Motor Neurone Disease Association of SA (or) MNDA of SA
Account No 27 062 913 0, Standard Bank, Rondebosch Branch 025009

It is hard to believe that the first half of 2009 will soon be something of the past. However, judging by the upcoming events listed in this newsletter, the second half of the year promises to be full of excitement. We would like to urge everyone to invite family and friends to attend these events in aid of the MND Association of SA.

I would like to take this opportunity to sincerely thank all the personnel of the MND Association of SA for their continued, unselfish dedication to our patients and their families. Despite difficult circumstances, they continue to offer excellent care. I would also like to remind our members and their families that they actually are volunteers (and not full-time staff) who make themselves available during weekdays to take care of patients. They can not be expected to be available at all hours, and we would therefore like to request that all after-hour issues be handled by the family physician or the local medical facility.

We hope that you find this issue of the newsletter enlightening and entertaining. As always, we welcome comments, questions and contributions.

Franclo Henning
Chairman, MND Association of SA

We say a big thank you to:

Mavis Kelly, Arthur Campbell, Masonic Bowling, C Eidelman, E Greenwood, Ingrid Gall, SJ Steyls, A Gilbert, G Conradie, AS Pepler, Kurt & Joey Strauss Foundation, CH Dose, and of course our regular monthly donors.

Kerry Bluett from England, lost her friend, Marina Beck, as a result of Motor Neurone Disease. Kerry decided to run the London Marathon in her memory and requested friends and family to sponsor her. We are extremely grateful to Kerry for putting herself to this test and to her friends and family who so generously sponsored her. Because of Kerry, we received the very generous amount of R7,800 in donations. Thank you so much ! (We may have missed a contribution where we were unable to identify the donor and/or reason, as no reference/narrative appeared on our bank statement).



Nicky Eldridge, whose dad Michael Swanson, from Cape Town, succumbed to MND in November 2006, once again held a "Coffee Morning" at her home in Wimbledon, UK, to remember what would have been her dad's 64th birthday in March 2009. With the help of her friends, she managed to raise R5,200 which has been donated to us. Thank you Nicky. Your efforts and the generosity of your friends, are greatly appreciated.

NEWS

From Dilys Jones who has joined the

SOUTHERN CAPE MND SUPPORT GROUP (From front page)

Our small group is active and continues to meet regularly. There are some logistical challenges in getting together because our members come from quite far afield in the Garden Route and little Karoo area, but we have been able to achieve our goal of meeting every six weeks.

Our first meeting was devoted to catching up on everyone's news after the December/January break and planning our activities for the year. Many of our members continue to be pressurised by well-meaning family members (and harassed by unscrupulous marketers) to try various "miracle cures" and we had a fruitful discussion about ways to

deal with this. Dilys Jones (speech therapist) spoke at our second meeting on managing the speech and communication difficulties often associated with MND and we had a look at “etriloquist”, an alternative/augmentative communication programme developed by an American man with MND which is available for free.

This year we have identified caring for the carers as a major priority. We had an informal coffee morning (called a “bitch and moan session” by one of our members with MND!) for caregivers and family members who were able to share their experiences and provide invaluable support for each other, and plan to continue to meet on a regular basis.

We would like to promote our group more actively this year and recruit some more members. We are planning to have some posters made for display in the local libraries and hospitals, and hope to have some newspaper coverage to coincide with World Motor Neuron Disease Day.

MAILBAG

Shirley MacLennan of Grahamstown, whose husband Don passed away in February this year, wrote this letter which is also a tribute to Don:

Don was sustained by dozens of messages while he was in hospital and by many visitors, all assuring him of love and concern. I am still sort of astonished that he could have died despite those strong currents of good will and the power of the care and good wishes surrounding him. I did not believe that he would part from us as he did, because he was so caught up in life and was looking forward to the next things: polishing the new poems, seeing Dress Rehearsal into print, and the next promised visits from our far-flung children and friends. I think that despite a preoccupation with death which began decades before the motor neurone disease, he too was caught by surprise.

We, Shirley, Ben, Joe, David, Susan and spouses, the grandchildren and the extended family who came to be with us over the weekend of the memorial at Rhodes Chapel and the climb up the Compassberg to scatter the ashes have similarly been sustained since Don's death by all the cards and phone calls and all the other kindnesses of friends. We deeply appreciate what so many people have said, have written, have cooked, have sung, have driven, have flown, have climbed, have been to us. We are indeed blessed in our family and friends.

Don could say now the lines from Kanzantzakis's grave which were written on the new T-shirt he wore in hospital after his stroke:

I want nothing
I fear nothing
I am free

And I would say something that resonates with a poem from Don's unpublished manuscript, a poem about the young Don and his dad talking long into the night about a golden journey to Samarkand, a city of wisdom and beauty, almond blossom, sherbet, and starlight. It was a journey the book-besotted dreamers never quite made. The poem ends with the practical mother Elsie MacLennan determinedly sleeping (dreaming her own dreams I wonder ?) through it all.

I have a new book, *Stoep Zen* by Anthony Osler, which gave me strength and calmness when Don went into hospital and I needed it most. I enthusiastically recommend it to anyone going through a rough patch, and to anyone who isn't. Osler is a Buddhist monk, a family man, and a human rights lawyer who lives on a farm in the Karoo. The book is imbued with his love of the land, the light, and the people.

This is the bit I want to quote:

“I lift my eyes to the Loskop and fear no evil
But if I don't watch my step I will fall into an aardvark-gat”

It's a bit like the quote which was up on the wall in front of Don's desk for many years. In Arabic script, in translated as “Trust in God, but remember to tie up your camel.”

Here is the last poem from *Dress Rehearsal*

In the beginning was the word
wedded to creation,
its sound the essence
of the world itself

Death will enter silently
a landscape of sky and clouds,
through my study window,
a hillside with burned pines.
I am the seed dying to live
in these familiar things,
perhaps bear fruit.

Thanks to Vivien and all of you for help so kindly given.

Living with MND - The Love of our Lives*(Extract from Spring 2009 issue of Thumb Print)*

Alan Crowley writes movingly about his wife Jane's determination to make the most of the time she had left:

My darling wife Jane was only 56 when she heard the horrific news that she had MND. Not only were our lives to be changed forever, but there was a sense of numbness as to what the future had in store. From the outset, as a committed Christian, Jane tried not to be fazed by her illness and remain positive. I can see her now, asking her consultant if she could go to Iceland, a place she had always wanted to visit. In May 2007 that's where we went for a great holiday.

We also made trips to see our son and his family in Lincoln, and travelled to London and Paris. Jane and I spent our honeymoon in Paris in 1974 and this time our daughter Liz came with us.

For what was to be Jane's last year, both Liz and I gave our time to Jane's needs. Jane never complained as this horrific illness began to take over her entire body. We enjoyed her last months to the full as much as we could. Our first granddaughter, was born in July. In October we made our final trip to London, meeting up with our son and his family to watch Liz take part in the first London Royal Parks Half Marathon. She raised over £2,000 for the MND Association.

Just four weeks later Jane died – for her it meant no more suffering, but for us and our friends, it was the greatest loss. Jane was a teacher who loved the English language. The love of her life was to read, but this was sadly taken from her as the illness progressed. Jane was a beautiful, intelligent woman who, like all with this disease, left us far too early. She was, quite simply, the love of our lives.

*A little girl had an earache and wanted a painkiller.
 She tried in vain to take the lid off the bottle.
 Seeing her frustration, her Mom explained that it was a
 childproof cap and she would open it for her.
 Eyes wide with wonder, the little girl asked: "How does
 it know it's me?"*

RESEARCH**New MND gene identified**

(Article taken from Spring 2009 issue of Thumb Print, MND Association Magazine, Northampton, UK).

A research project involving Prof Christopher Shaw at

King's College London, has yielded an important breakthrough in MND research. The work was funded in part by the MND Association.

Working with MND researchers at Harvard University, USA, Prof Shaw's team has found that mutations in a gene called FUS cause MND in some families affected by the rare, inherited (familial) form of the disease.

Following up on a lead about mutations in FUS from the US researchers, Prof Shaw's team confirmed that mutations were present in 4% of UK patients with familial MND. Familial MND accounts for 10% of all cases of the disease.

Prof Shaw's team went on to demonstrate that the mutant FUS protein behaved abnormally in cells and accumulated in the motor neurons of people with this form of MND.

This is the second MND-causing gene to be identified in less than 12 months, a reflection of the accelerated pace of research around the world. A gene connected to a protein called TDP-43 was identified in March 2008, and now FUS in March 2009.

What does this research mean to somebody affected by MND ?

Mutations in the FUS gene are very rare and account for less than 1% of all cases of MND. For the families that are affected by the FUS gene mistake, a future test to identify the mutation may become available.

This discovery helps to glean a deeper understanding of what causes all types of MND. Investigators believe that discovering the genetic cause of familial MND will lead to a better understanding of what is going wrong in the more common, sporadic form of MND – as sporadic and familial MND are clinically indistinguishable, scientists believe that the mechanisms underlying both types of the disease might be similar as well.

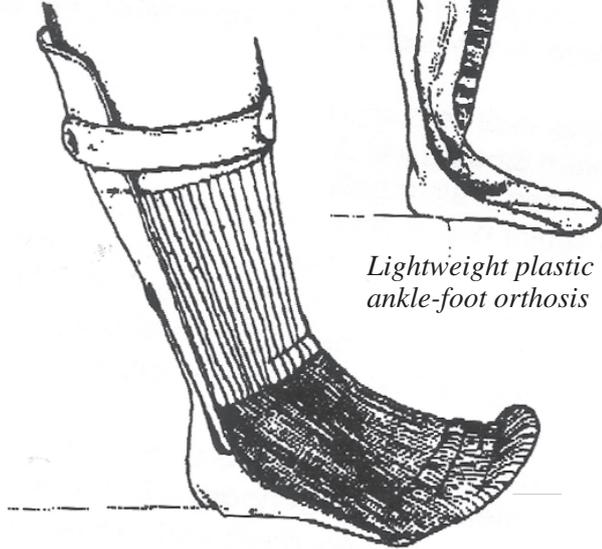
Prof Shaw says: "We are extremely excited by this discovery which has come after many years of painstaking research. The collaboration between the Boston and London research groups has been crucial to this breakthrough.

"Fus provides another powerful clue as to what causes MND. It is only in understanding the fundamental disease mechanisms that we will find a cure".

*Sleep is a healing balm for every ill.
 Health, the greatest of all we count as blessings*

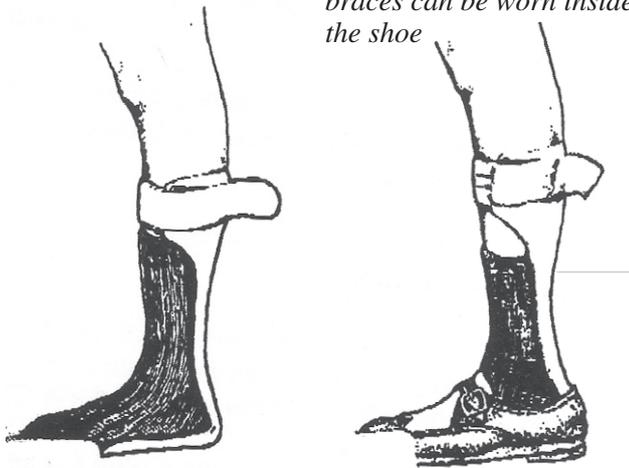
Orthotic Devices

Plastic orthosis in position



Lightweight plastic ankle-foot orthosis

Metal ankle-foot



Metal or plastic braces can be worn inside the shoe

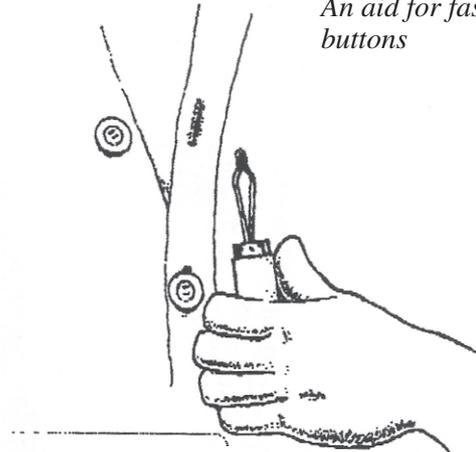
Dealing with leg and ankle weakness

Orthotic devices are applied to the patient's body to provide SUPPORT.

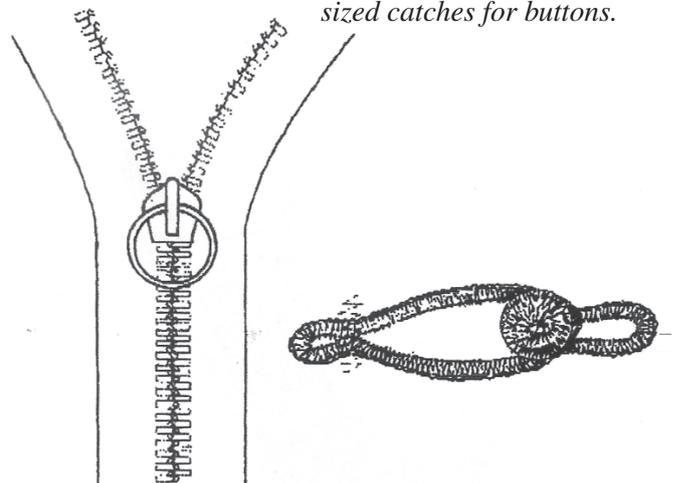
The Motor Neurone patient who has developed weakness in the muscles of the foot and ankle may have problems with stumbling, especially when going up or down stairs, roadside curbs or uneven surfaces. The weakened muscles result in a problem called "footdrop", which leads to stumbling. This problem can be reduced by an Ankle-Foot orthosis, which will be a lightweight plastic splint. They are made up very quickly to the shape and size of the individual's leg and foot. They fit into the shoe and are very comfortable. Your doctor can advise on the nearest place for one to be made.

Clothing

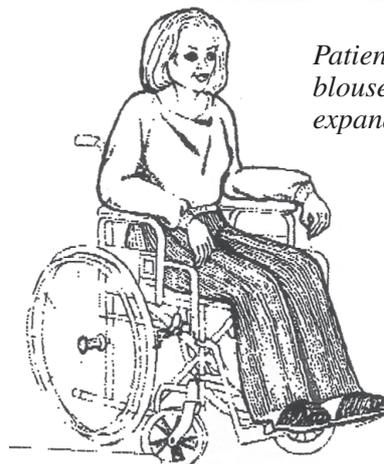
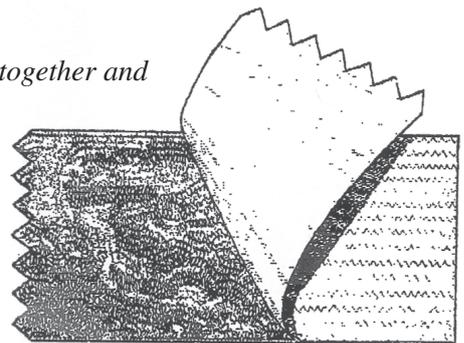
An aid for fastening buttons



Zipper with loop, and over-sized catches for buttons.



Velcro "sticks" together and pulls apart.



Patient wearing a pullover blouse and pants with an expandable waist.

Since most clothing is fastened by means of buttons or zippers, the MND patient with reduced manual dexterity may find it difficult to put on clothing. There are several ways to manage this problem. Fat-handled devices for grasping buttons or zippers can be purchased at your nearest Roll-in-Centre (formerly known as the Independent Living Centres).

Oversize buttons or zippers, some with large loops for grasping can be attached to your favoured clothing. Velcro in place of buttons, key rings attached to the hole in the zipper. Clothing which has no fasteners at all, pull on pants and loose over the head clothing. The ease of turning in bed at night can be helped with satin nightwear and sheets. This fabric slides on itself much easier than cotton or fleece.

Motor Neurone Disease and the Family

MND affects the whole family. It will have an impact on every member and as the person with MND loses employment, mobility, independence and communication many changes will be forced onto the family and adjustments will have to be made by each member as roles are reassigned and lifestyles changed.

Although its effects may be considered, the illness should not be allowed to control everything within the family. The needs of the person with M.N.D. do not always have to come first: other members also have needs and rights and their long-term interests should not be forgotten.

Many families have difficulty talking about what is happening and its effect on individual members. Encouraging open communication within the family helps to counteract the isolation that may be felt by each person and increases understanding and awareness between members.

Where there are children

Children will usually know something is wrong by the changes in parental behaviour and attitude and they will be more adversely affected by being excluded from what is happening than by being involved in the family distress. Their ability to understand the illness and its implications will be influenced by their age and intellectual development and they need to be given an explanation in words and ways that recognize this, and be included in family discussions wherever possible and appropriate.

Someone they love and trust should give children simple and truthful information. This is generally a parent, but parents may need encouragement, help and support to enable them to do this. The time after diagnosis is par-

ticularly stressful for parents when they themselves are emotionally vulnerable and trying to sort things out in their own minds. It is difficult for them to explain things that are not clearly understood, where so many uncertainties exist about timescales, future course of the illness and its effects on the family. Thinking about the future is emotionally painful and talking to their children about the illness is a forceful acknowledgement of what is happening.

Children may develop many fears and fantasies and become very frightened as they watch a parent regress to dependence and possibly become emotionally instable and angry. They need to be able to talk about their feelings and fears in a safe atmosphere and be given appropriate reassurance. Practical questions, such as what is going to happen to the family after the parent's death also need to be answered.

Many children become involved in the physical tasks of caring for the parent and obtain much comfort from this. It is important, however that the tasks are appropriate for the child and not burdensome and stressful.

Memory boxes are fun to do with photographs and written stories of all the happy times spent together.

Notify schools about a parent or grandparent in the case of very young children, so that they can monitor any behaviour changes. If teachers are not aware of this and the child starts bullying or not doing homework he or she will be underservably disciplined.

We hope this will help a little, and remember to love, hug and kiss your children lots.

RECIPES (Ensure®)

Breakfast (Serves 1)

100ml Oats Porridge

100ml cold water

250ml hot water

4 scoops Ensure® powder

Pinch of salt

Mix oats and cold water in a saucepan. Place on heated hot plate and add 250 ml boiling water. Bring to boil stirring continuously. Turn down heat and simmer until done. Just before serving stir in Ensure® powder. If desired, add chopped banana or walnuts.

*For extra protein add two scoops of Promod®

Coffee

1 level teaspoon instant coffee added to 50ml Ensure®. Stir well and add remaining 200ml and stir again. Sprinkle with cinnamon or nutmeg if desired

Honey

Mix 1 to 2 teaspoons of honey together with the Ensure® in a blender. Blend well.

Scrambled Eggs

2 Eggs
100ml Ensure® natural
Knob of Butter/Margarine
Seasoning

Beat together the eggs, Ensure®) and seasonings. Melt the butter/margarine in a saucepan. Add the egg/Ensure® mixture and cook gently until soft and creamy, stirring occasionally.

*For extra protein add two scoops of Promod®

Bran Muffins

500g Golden Cloud Bran Muffin Mix
375ml Ensure® Vanilla
1 Egg
25ml canola oil
125ml raisins
80ml chopped pecan nuts (optional)
Mix all ingredients together to form a smooth batter. Spoon into greased muffin pans filling cups about three quarter full. Bake at 180°C for 20-25 minutes.

Tomato Soup (Serves 2)

Half a can condensed tomato soup
200ml Ensure®natural
Mix condensed soup and Ensure® in a pan and warm gently. Do not boil. Add water to thin soup if desired.

*Try different flavours of condensed soup, eg. chicken, mushroom

Ensure® Bread & Butter Pudding (Serves 6)

600ml Ensure® Natural/Vanilla
8 slices buttered bread
75g seedless raisins/currants
3 large eggs
5ml cinnamon
Preheat oven to 180°C
Cut bread into triangles and arrange in a buttered ovenproof dish. Beat eggs and Ensure® together and strain over the bread. Sprinkle with cinnamon. Bake for 45mins or until custard is set.

Ensure® Mashed Potatoes

200g potatoes, peeled
100ml Ensure® natural
butter to taste and seasoning
Boil potatoes until cooked. Drain all water and mash the potatoes. Add Ensure® and butter as required. Season with salt and pepper and beat to smooth consistency.
*For extra protein add 4 scoops Promod®
*Add chopped parsley

* Promod® is a condensed protein powder

*They may forget what you said,
But they will never forget how you made them feel.
~ Carl W Beuchner ~*

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.

Condolences to the family and friends of:

Donald Maclellan, Rita Bartlett, Mavis Christopher, Mike Fritz, Marga Kruger, Pauline Magennis, Pierre Goosen, Jeanette Janse van Vuuren, Jennifer Gibson, Francois Majoos, Mark Agrella, David Binedell

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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