

HINTS:

1) Never let anyone help you up by the arm - even if you don't think your arms are affected.

We didn't know this and I used to help my husband up by his "strong" arm and he ended up with a torn tendon in the right shoulder. Have them use a rolled up towel (passed around the back and under the arms with two ends to pull on), a lifting belt (which has handles all around it) or bend their knees, flatten their back and put their arms around your back.

2) This tip might be useful to any ladies out there with MND -

I was diagnosed with MND two years ago. I have a full and active life still but obviously have difficulties with some things. One of these was turning over in bed at night. I was given a medieval looking bar by Social Services but did not like this at all. At Christmas my daughter bought me a pair of satin pyjamas and hey presto! problem solved. They slide and so now turning over is no problem at all. I was thinking of also getting satin sheets but can imagine me shooting rapidly from one side of the room to the other if I do! Sorry but I have not seen satin pyjamas for men but who knows there may be.

INSOMNIA or difficulty with sleeping -

Causes:

- 1) Discomfort arising from immobility
- 2) Pain due to stiffness of joints or muscles
- 3) Muscle spasticity
- 4) Shortness of breath
- 5) Excessive saliva or dry mouth
- 6) Taking stimulants at bedtime
- 7) Anxiety

Strategies:

Try not to remain in the same position in bed for too long

Satin or silk sheets may be helpful moving about in bed

A segmented or egg-box mattress, on top of your own mattress, to distribute pressure more evenly

Muscle spasticity may be relieved with medication - consult your doctor

Joint pain may be relieved by stretching, or a range of motion exercises - See a physio.

Breathing can be helped by elevating the head and chest with extra pillows.

This relieves pressure on the diaphragm and improves lung expansion.

Sometimes a fan or oxygen may be necessary.

Before going to bed avoid conflict, violent T.V. shows, over-exertion, caffeinated beverages, smoking, and heavy meals. Too much food puts pressure on the diaphragm and aggravates breathing problems.

Retire at the same time each night and reduce day time napping. Make sure the bedroom is well ventilated and light bed-clothing is used to allow easier movement and prevent perspiration.

Impaired swallowing reflexes may cause choking on saliva or mucus. This is annoying, especially for those with an ineffective cough. Sleep with the head elevated to prevent secretions from moving toward the cough reflex center. See a doctor for medication to help.

A slow rhythmic back rub or a light massage of aching muscles promotes relaxation. One exercise for reducing stress is deep abdominal breathing. Chat to a friend or doctor to help with family issues. Soft music and reassuring conversation.

COLD LIMBS

People with M.N.D are prone to feeling cold.

Strategies:

- 1) Wear warm clothing. Wool is better than synthetic materials.
- 2) Use sheepskin slippers, seat pads, woollen or arctic fleece rugs and leg warmers.
- 3) Gentle massage and frequent changes of position help circulation and stimulate warmth.

SWELLING OF THE HANDS AND FEET

Swelling may be caused by a build-up of fluid in the tissues, especially in the feet and legs. It is important to consult your doctor, as there are several possible causes. In M.N.D it is most likely to be due to poor circulation resulting from inactivity and the effects of gravity. Occasionally the hands are affected as well as the feet and legs.

Strategies:

- 1) Keep the affected parts elevated on cushioned support
- 2) Massage and gentle exercise will help to disperse the fluid

- 3) If in a wheelchair make sure that the pressure is taken off the thighs by either raising the foot rest or suitable cushions
- 4) Rest the hands on broad chair arms when sitting supporting the entire arm comfortably
- 5) Don't wear restrictive tight clothing around ankles or wrists

RESEARCH

Professor Ian Trowce (Melbourne Univ.) - Mitochondrial handling in ALS: Mitochondria make the energy for cells to function properly, and also control the levels of calcium in the cell. If calcium is not properly controlled it becomes toxic and may cause the death of motor neurones. This project will use the mouse model to test the possible relationship between the SOD1 mutant gene and mitochondria dysfunction. If successful it will focus the development of therapies aimed at reducing the interaction of the SOD1 mutant gene with mitochondria.

From Rodney Harris

Visit the ALS/MND Newsroom at www.alsmndalliance.org. A new article by Andrew Eisen MD, F.R.C.P.C, Professor Emeritus, Director of the ALS Clinic, Vancouver General Hospital and the University of British Columbia, has been submitted addressing the issue of unproven therapies and ALS/MND. This article was commissioned by the Alliance to address concerns regarding unproven therapies.

POSITIVE THOUGHTS

Fight for Life

When I was told I had MND I steeled myself to fight it. Though I knew at the time there was no cure, I looked for things to do that would keep me occupied and stimulate my brain. The manual work I used to do was now impossible so I planned to do something new. My inspiration came when I saw Prof Stephen Hawking on TV.

I recognised that despite his diagnosis, Prof Hawking had chosen to put his brainpower and education to good use. I realised that I needed something that would provide me with a similar challenge. Without this brainpower, I also recognised that whatever I chose needed to be something I could finish. The inspiration came a few days later when my daughter-in-law called with my granddaughter. As we talked I realised I knew nothing about my paternal grandparents. Knowing my life might be cut short I decided to write an account of my life so that my own grandchildren might know a bit more about me.

I gave myself only one rule - to write it as best I could and enjoy doing it. That manuscript took nearly two years to complete, but the interesting thing is that my condition did not decline as fast as my doctors expected it to. This fact is reflected by the number of times that I need to go for checks on the progress of the disease. My hospital visits have gone down to every six months from every three months.

As I was writing my life story I also found another challenge: painting, using watercolours. This offered a useful alternative to my writing, and gave me a second string to my bow. By changing from one to the other I found I was always fresh to continue working. My ambition remains undaunted and is as strong today as when I started. This has not only kept me occupied, but also stopped my feeling sorry for myself. Indeed in a lot of ways I feel a better person for my achievements with the pen and the brush.

Another side to all this is how it affects the carer. Their job is a lot easier when the person they are caring for is content. Don't forget that carers have feelings too.

If you are being cared for by a partner then a hug and a kiss means the world to them. If your carer is from outside the family try to be polite; please and thank you cost nothing yet they mean such a lot. If you know a joke or can see the funny side of something then share it with your carer - it breaks down barriers and leads to a happier life. The same can be said of your friends and visitors, they'll be more likely to call again.

So where is all this leading? It's a simple guide for a more content and better life, for both patient and carer. It's made the future easier for me to face. I accept that not everyone will want to write or paint, but there are many other options.

Remember you only get out of life what you are prepared to put into it. Life does not stop the day you receive bad news, but it can be more bearable if you fight for it.

REMEMBER - A happy patient makes a happy carer, and a happy carer will always make an extra cup of tea!

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Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



Mandy Snyman of Port Elizabeth with her mom, Marie Gurr, enjoying her 40th birthday party on 1st August 2003, organised by her family and friends.

**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. Peter Kraus

VICE CHAIRPERSON
Vivien O'Cuinneagain

TREASURER
Bunty Money

SECRETARY
Vivienne Zilberg

INT. ALLIANCE REP.
Diane Heron

ACKNOWLEDGEMENTS

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

The AGM was held on 10 September, an evening I always enjoy. A time to meet old friends and new patients with their families, as without you there would be no reason for our existence. It is occasions like these that re-enforce our mission and focus our goals for the year ahead.

Being re-elected to the Chair is indeed an honour and a privilege. I thank you for showing confidence in your committee by re-electing each member to their portfolios. Our commitment to providing and promoting the best possible support to you and your family remains our prime goal and function.

Everyone goes through hardships in life. Adversity only makes us

stronger. The more we go through, the more we learn and grow. When we have learnt our lessons, the pain usually goes away.

However, through all this, may you recognise the presence, power and light of your soul in life. May you realise that you are never alone. May you respect your own individuality and realise that you are all unique. Your destiny on earth is special and behind the façade of your life is something good.

Wishing all you special people fulfilment of your dreams !
Dr Peter Kraus
Chairman

NEWS

CONDOLENCES to the Family and Friends of:

Crystal Warner, Mirtle Burgess, N Dodman, Christopher Borchers, Klaas Mouton, Trude Hennessey, Rupert Watt, Brian Gravestock, Francis Eagar, Connie Coetzee, Tallie Taljaard, Katherine van Aswegen, Tjaart Steyn, Moyra Grobler, Yacoob Khan, Pieter Hattingh, Rene Honey, Cecilia Stemmet, Kathy Gullet.

INTERNATIONAL ALLIANCE SYMPOSIUM

Sisters Vivian O'Cuinneagain (Cape) and Liz Keth (Gauteng Area) will be attending the International Alliance Symposium in Milan in November 2003.

The Rotary Club Strand who twinned with Rotary Club Bregenzerwald in Austria

to raise the funds, presented a Breathing Machine to MNDA. This was handed over to Annetjie Schwartz, an MNDA patient, at

a Rotary Dinner on 26 June 2003. The photo shows Annetjie and her husband Steven with the outgoing president John Oxley (left) and incoming president Marc Stuyck.

PATIENT GET-TOGETHERS

INVITATION TO ALL PATIENTS and FAMILY and FRIENDS: - CAPE TOWN

1 November 2003 @ 14h30 at The Pinewood Village
Community Centre, University Drive, Pinelands
PLEASE RSVP - VIV ZILBERG - TEL : 021-5319744

- PRETORIA AREA

1 November 2003 @ 14h00 at The Centurion Hospice
Cnr North & Clifton Streets, Centurion

- JOHANNESBURG AREA

8 November 2003 @ 14h00 at The Ferndale Recreation Centre
Cnr Main & Harley Roads, Ferndale
PLEASE RSVP - LIZ KETH - TEL : 011-7914739 or 082 878 3716

OPEN GARDEN DAY - CAPE TOWN 25 OCTOBER 2003

12 Lincoln Drive, Bishopscourt (From 9 am to 5 pm)
Entrance Fee R20,00 (including Tea)

Margot Gawith has once again offered her spectacular garden, which is occasionally opened to the public, to us, as a Fundraiser. Please tell your friends about this fantastic opportunity to spend a relaxing time wandering through this parklike garden.

We do however need Volunteers to work on a shift basis, manning the Gate and assisting with the Tea Garden.

Please phone Viv Zilberg on 021-5319744 if you can assist in any way.



John Oxley, Marc Stuyck, Annetjie Schwartz, and husband Steven

MAIL BAG

Dear Vivienne x 2 and all the readers of this excellent and uplifting newsletter for all of us struck-down by this strange, unknown disease.

This is a "first" for me, as I have only been formally diagnosed in April after having undergone a major spinal operation in January because of two slipped discs in my neck which, alas, did not turn-out to be the cause of my increasing lameness, but MND. When the neurologist told me the news, and after taking a big "sluk", I asked him whether it was OK for me to go on a major overseas trip, which we had planned long ago? He replied succinctly: "circumvent the world, my friend, as long as you still can". (As an aside I must tell you that I still walked into his office on a stick and promptly tripped over his stupid Persian carpet and fell at his feet, to which this typical dry quack remarked: "now that was a

dramatic entrance!" I have since moved to the comforts of a wheelchair and rely on the assistance of many sweet people.)

So off we went - my wife Brenda, moi and trusted Saturn - on the following tour:- (N.B. please fasten your seat- or any other -belts you might have!)

Cape Town - JHB - Frankfurt - New York - Miami - Grand Cayman Island - Miami - Cancun (Mexico) - New York - Frankfurt - JHB - Cape Town; with a few road trips in between. Some of the transfers from and to the planes were rather adventurous, like when I had to be carried down and up again by two strapping Caymonnians, which was so funny. Not so funny was seeing the lonely figure of my son on the balcony of this minute airport, watching his Dad being carried down the steps after all the other passengers had long gone, and bravely waving and



Joe Stauch and the Caribbean Sea

smiling to me: - what must have gone through his mind at that time??! I was overcome with all kinds of emotion at that time: joy at seeing him, heartbreak at knowing what he had to deal with et al.

Well, let me not get soppy now. It turned-out to be a most amazing and rewarding holiday, mainly because I could see again - and in some cases, I am sure, to take my leave from - so many close friends which my wife and I had had the pleasure of meeting during the 30 years in the SA Diplomatic Service, as well as a fair sprinkling of family members in Europe. I chose the above photograph which in a deep kind of way encapsulates all the thoughts and feelings that went through my mind while staring into the deep turquoise horizons of the Caribbean Sea, contemplating my future as a heavily disabled person - yet experiencing such waves of compassion, love and affection, and not only from people I knew, but from complete strangers.

One of the most wonderful experiences since the fateful diagnosis in April has been the depth of intimacy expressed and felt by me and those closest to me: a truly new dimension of feelings. I was prompted to write an article for THUMBS-UP by Mark Alexander's contribution in the Sept. 2002 edition. He concluded with these words: 'Come, I will show you the way as I follow Jesus'. Bless you, Mark, and all you readers. If it had not been for my unbending faith I would have long given up on my new-found hope in Jesus.

I rest in the knowledge that this is but a flicker of an eyelid in my long and beautiful journey with God: come fly with me ! Warm regards.

Joe Stauch 30.07.2003
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From Jill Mackenzie, Port Elizabeth (Widow of Bill Mackenzie)
31 July 2003

Dear Viv

I don't know if you remember seeing dear friends of mine, Nin and Mick Badnall in Cape Town, probably beginning of 2002. Mick died in Vancouver Island this last weekend. He was diagnosed with MND in January of 2002 and Bill was diagnosed in May 2002. Nin was the dear Hospice Sister who was my mentor when my late daughter was so ill with a brain tumour 20 years ago and we became dear friends. Mick and Bill got on very well too. We could not believe that our two dear husbands had been diagnosed with this terrible disease.

I was also very sad to hear that Rupert Watt had passed away this last weekend too. We all had tea together with the Hospice sisters and Mandy. I popped in to see Mandy this afternoon. She is such a wonderful young person and is still busy on her computer. She had so much to offer with her wonderful music talents, but she has so bravely adjusted her life.

I am getting used to life on my own slowly. Bill and I were going overseas this year as it was our 50th wedding anniversary year and I have decided I must still go. I will be leaving on 23 August.

I will be sending a small donation in memory of Mick Badnall and Rupert Watt.

I did speak to the Neurosurgeon about Bill's file and he said it could be released for research should it be requested. I don't know if there is any follow-up on these people.

My grateful thanks to you and your team for the help you gave me when I needed it.

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A Poem Cycle (by Millie Brock, January 2003 – Aged 7)

"Never give up"

If you give up on something, you might not get it
But if you try you might get it, before you die

"I'll always love you"

But if I don't I'll be above you
I am in heaven And you are now below
When you come up – You and I will follow

"My dream is to fly"

My dream is to catch a butterfly – My dream is to live happily ever after
But sometimes things come up, and they might stay.

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.