



MAGAZINE OF PARKINSON'S QUEENSLAND INC.

the Quarterly

www.parkinsons-qld.org.au

Spring 2009

Awareness for Parkinson's

Welcome to an earlier than usual Spring issue of your *Quarterly* magazine.

This is due to two important upcoming events; the Qld Walk for Parkinson's and the Annual General Meeting. We need to be very aware of these significant events as they are most relevant to the well-being of the Parkinson's Queensland Inc. organisation.

Firstly, PARKINSON'S AWARENESS.

This year from August 30th through to September 5th is **National Parkinson's Awareness Week**. Let's all get on the awareness 'bandwagon' and help to inform our communities about Parkinson's disease and how it impinges on you, your lifestyle, family and friends and ultimately as a cost to the community.

The **Qld Walk for Parkinson's** will round off the week, as many of us participate in this event. If you cannot attend, you may want to sponsor or donate to participants for their effort in the walk (myself and many others included).

Secondly, we are nearing the date for PQI's Annual General Meeting set down for September 12th, 2009. It would be inspirational to see as many members as feasible at this year's AGM. See you on the day.

Reading through the following pages, you will find articles of specific interest to you, whether you be a Parkinson's sufferer, carer, family or friend.

We have a collective message from our President, Judy Rawlins, and Vice-President, Neil Page. There is news from the Mt Gravatt and Logan support groups and more on our new and current merchandising items.

The research articles from around the globe are varied in nature with emphasis this issue on some research into the non-motor symptoms of Parkinson's disease (PD) and some exciting new hope that has been sparked through Spinal Cord stimulation.

Other articles are on self-help, the susceptibility of illness of carers, plus doctor/carer communications.

Backing this up is an unforgettable look at the past, some ideas from the *Masterchef* kitchen and then a good-humoured column of jokes and quotes.

The contact names and phone numbers for the PQI support groups are listed on the back page, as are the recent general and memorial donations.

So make the most of this issue of *the Quarterly* and encourage others within your social network to read this issue with much enthusiasm as well.

Until the next issue, take care.

Kevin Robins - Editor

Qld Walk for Parkinson's
Entrant 1055
"Have thongs will travel!"



"Qld Walk for Parkinson's" - Sunday 6th September 2009

This is our major fundraising event for Parkinson's Qld Inc during **National Parkinson's Awareness Week**. Arrangements are well under way and we are moving positively towards the success of the "Qld Walk for Parkinson's" event which will be held on the Wynnum/Manly foreshore commencing at 10:00am from the Sea Scout Hall at Darling Point. The walk is for people of all ages and fitness levels, and the event will be from 1 to 4 kilometres in length.

It is not a race but an enjoyable fun and family day's stroll. There will be ample car parking space for everyone. There will also be major prizes and give-aways. We will need the full support of all Parkinson's Queensland members **and** their Support Groups in supplying entrants as well as sponsors for those entrants.

Make sure you circle this date in your diary and invite all your family, friends, children and grandchildren to come along for a fun-filled day down by the bay.

You can either enter the event, become a supporter/sponsor for the walk OR donate to sponsor those people who have already entered for the walk.

All details are shown on the dedicated website, www.qldwalkforparkinsons.org.au



What's Inside	Message from Judy and Neil <hr/> Spotlight - New Staff Member	Support Group News <hr/> Seminar Announcement	From Around the Globe <hr/> Merchandising	Self Help <hr/> Communication <hr/> Good Old Days	AGM Notice <hr/> PQI Support Group Listing
----------------------	--------------------------------------------------------------------------------	----------------------------------------------------------------	------------------------------------------------------------	------------------------------------------------------------------------------	-------------------------------------------------------------

Committed to Caring:*The Power of Many ... 1 Team*

Patron • Prof. P. Silburn
President • Judy Rawlins
Vice President • Prof. Neil Page
Treasurer • Errol Gilbert
Secretary • Lenore Bateman

Committee Members

- Alwyn Boyle
- Joy Boyle
- George Edwards
- Mavis-Ann Edwards
- Dawn Evans
- Assoc. Prof. Graeme Kerr
- Sue Page
- Kevin Robins
- Joy Schilling

Corporate Advisory Panel

- Angela Sheehy
- David O'Brien
- John Bird

Parkinson's Queensland Inc.

Ph: Freecall 1800 644 189
(07) 3209 1588
Fax: (07) 3209 1566
Address: Unit 2/25 Watland Street
Springwood Qld 4127
Postal: PO Box 1684
Springwood Qld 4127
Email: pqi@parkinsons-qld.org.au
Web: www.parkinsons-qld.org.au

Office Staff:

Director of Services
• Jane Hulands
Administration Officer
• Janelle
Information Officer
• Rebecca Saunders

Office Hours:

Mon – Fri 9:00am to 5:00pm

A special thanks to the volunteers who are so essential in keeping Parkinson's Queensland Inc going.

Magazine Editor: Kevin Robins
email: kevinrobins@iinet.net.au

Advertising Enquiries

Email: pqi@parkinsons-qld.org.au
Phone: (07) 3209 1588

Inside this issue

1. Awareness for Parkinson's
- Qld Walk for Parkinson's
2. Parkinson's Qld Inc Information
- Message from President and Vice-President
3. Support Group Reports
- Mt Gravatt, Logan and Caboolture
4. Welcome Rebecca Saunders
- Craft and Information Stall
- Parkinson's Seminar
5. Non-motor Symptoms of PD
- Therapeutic Target for PD
6. Spinal Cord Stimulation Hope
7. Caring for the Carer
- Volunteers Needed
- Your Contributions
- Merchandising Items
8. Self-Help
9. Improving Communication
10. The Good Old Days
- Commonwealth Respite and Carelink Centre
- LSVT-Global
11. *Masterchef* Kitchen Recipe
- Ode to Parkinson's
- Jokes and Quotes
12. Annual General Meeting Date
- PQI Support Groups
- Donations and In Memory

- Deadline -

All submissions for articles or advertising in the next magazine must be received no later than **November 18th, 2009**

→→ If you wish to receive future magazines by email please advise the PQI Office. Each issue will then be forwarded to your email address as the Parkinson's Quarterly e-magazine. Of course, this will save significant funds which can be redirected to other Parkinson's Qld Inc activities.

Message to Members

This is the last Quarterly issue before our 2009 Annual General Meeting (AGM) and so it is a good time to reflect on and record progress since our last.

This year has been a year of re-building – we now have three (3) staff members, a new website, regular news-filled publications, re-vamped information and awareness programs, a growing network of Support Groups and substantial fundraising activities - all this over and above the day-to-day services provided by phone and mail to individual enquirers.

These achievements have been made possible by the dedication and hard work of PQI's staff, volunteers and Management Committee. We would like to record here our heartfelt thanks for the work that they have put in, often in very difficult circumstances.

PQI now needs your help in taking the organisation further. Details of the 2009 AGM are shown elsewhere in this issue. Please come, participate in the decision making and so ensure PQI remains focussed on the things important to you.

Judy Rawlins
President



Neil Page
Vice-President

ANNUAL GENERAL MEETING

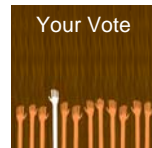
Annual General Meeting will be held on 12th September 2009

Venue: Logan Uniting Church – Springwood Qld 4127

Time: 10.30am to 12.30pm

Details for the AGM are on the back page.

Your Vote

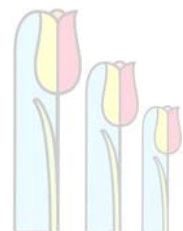


Life isn't about the number of breaths we take, but the moments that take our breath away.

Disclaimer

Parkinson's Queensland Inc. has endeavoured to ensure that the information in this magazine is accurate, however, we accept no responsibility for any errors, omissions or inaccuracies in respect of the information contained in the material provided by PQI. Nor is the provision of material by PQI to be construed as any representation that there is no other material or information available in relation to the information provided. Further, PQI accepts no responsibility for persons who may rely upon this information for whatever purposes.


hacc
 home and community care
 A JOINT COMMONWEALTH AND STATE/TERRITORY PROGRAM
 PROVIDING FUNDING AND ASSISTANCE FOR AUSTRALIANS IN NEED



Mt Gravatt Support Group

The Mt Gravatt group has been together for a long time and meets once a month at the Garden City Library on the 4th Monday of each month.

The main theme of the group is friendship, support and information. This year we started with a fun movie and everyone got a lolly bag (complete with Jaffas) to enhance the day. We are noted for our love of a laugh and the speakers that we have visit often hang around after they've finished to soak up the fun and enjoyment.

We have all become such good friends as we struggle with our individual symptoms. Last month, we went out for lunch to the Redlands Sporting Club for a buffet lunch which was great. This month we will have a lady who began writing novels later in life and is still getting great satisfaction and recognition for her work. She has visited us in the past and is delighted to be asked to return. At the end of the year we always have a break up lunch. Last year we went to the Southside Workers Club and all the tables were set up beforehand and everyone got a hand-made placemat and chocolate box to take home.

I am very blessed to have good support from carers within the group who can make sure that it will go ahead if I cannot be there on the day. Even though there are some of us who have lost a loved one, we still stay part of the group because of the friendships we have formed.

Dawn Evans and myself have just had a Craft and Parkinson's Awareness stall at our local shopping centre, with great support from Nell Peterson, our families and Julia Robins who isn't even from our group. \$367 was raised & it was a long, but great day.

Why don't you consider approaching your local shopping centre to secure a free spot? It's a great way to let the public know about Parkinson's disease and raise awareness in the community.

I consider myself privileged to serve my friends as I co-ordinate a group on behalf of those who live with Parkinson's disease and their families.

- Mavis Edwards

Logan Support Group Bus Excursion

It's 8:15am and most of our group are looking at our watches and taking note of who has not turned up for our bus excursion to the mouth of the Brisbane River.

Fortunately everyone is ready and willing to get going. George Edwards, our volunteer driver, starts to round us up so we can hit the road.

We take the scenic route, driving past some of the magnificent properties along Ford Road in Rochedale, on the way to the lovely bayside of Wynnum/Manly.

By this time, some of our members had to be restrained from singing, as they were drawing attention from various people driving cage like vans, who were carrying, what looked to be huge butterfly nets and white straight jackets.

We finally convinced George, our driver, that he shouldn't be driving with both hands over his ears and we progressed to the very interesting Port of Brisbane, where we were met by Peter, our tour guide leader.

After the usual coffee break, and convenience stop,

Peter boarded our bus and directed George to the various sites, which everyone thoroughly enjoyed. We would recommend anyone who has not visited the Port of Brisbane to do so. There are nice gazebos and for those more inclined, a restaurant/café which caters to anyone wanting a meal or snack. I should mention here that appointment times are essential, mainly so the tour guides can plan their itinerary.

After the tour and inspection of the catering facilities, we adjourned to the Manly Leagues Club, where we had a nice lunch which was very reasonably priced.

Eventually with the fear of being kicked out, we drove on to Manly where we had more coffee, cake and biscuits, and took some nice photos (see below).



Without exception everyone had a great day and we look forward to our next outing, which will probably be a Logan Garden club bus excursion, in September.

- Bob Vickers

Join a Parkinson's Qld Inc Support Group

Now these two articles from both Mt Gravatt and Logan Support Groups must surely represent some idea of the benefits of joining a Parkinson's Qld Support Group. The joy and friendship, comfort, and sense of belonging are worthy attributes, not to mention the up-to-date information that is distributed monthly from the PQI office onto the Support Group Coordinators.

The value is immense. The group interaction within is always relevant, as is the regular guest speakers who are organised by either the group coordinator or PQI. So, come on - join a Parkinson's Qld Support Group near you. New members are always welcome.

Everyone understands your Parkinson's situation, whether being a sufferer OR a carer, family or friend.

For information on locations, please refer to the back page where coordinator names, contact details, the time and date for the group are conveniently listed.

Group Birthday Congratulations

Congratulations to members of the Caboolture Support Group who recently celebrated their 20th birthday.

Neil & Sue Page had a very pleasant visit to the birthday celebrations with Judy Rawlins. The support group put on a wonderful meal and lots of door prizes.



In the Spotlight

Hello! My name is Rebecca Saunders and I'm the new Information Officer at PQL. I've been extremely busy settling in during the past month, but I've already been fortunate enough to meet many of the lovely PQL 'family' - including the Management Committee, volunteers and members.

I will be primarily responsible for the research and dissemination of current information about Parkinson's disease, and my role is to ensure that the needs of people with Parkinson's are being catered for. I'll also be actively involved with service providers, health care industry professionals and the wider community.

I have a Bachelor of Journalism and have worked in a marketing and communications position for the past 6 years. I recently became engaged and am busily planning my wedding in April of next year.

In the coming months I'll be visiting many local support group meetings and I look forward to meeting many of you there. I'll also be attending several health expos, so please feel free to come along and say hello!

You are more than welcome to contact me at anytime if you ever need any assistance – I'm only too happy to help you in any way possible. Currently I'm in the office on Tuesdays and Thursdays, and I can be contacted on 0403 309 099 or at info@parkinsons-qld.org.au.

"Volunteers are not paid anything, not because they are worthless, but because they are priceless."

Springwood Combined Craft and Information Stall

The Mt Gravatt Support Group recently held a combined craft and information stall at Springwood Shopping Centre and successfully raised \$367 for Parkinson's research and support services.

Mavis Edwards and Dawn Evans worked tirelessly to organise the stall – congratulations on such a fantastic effort! Special thanks must also go to Dawn's grandchildren who helped out on the day and to Aubrey Evans for crafting many of the items for sale at the stall.



Mavis Edwards and Dawn Evans proudly displaying their craft and information stall

ADVERTISEMENT

Neurologists at the Royal Brisbane & Women's Hospital are seeking participants for a clinical trial of desmopressin tablets. Desmopressin has been used to control bed-wetting in children for several years. We are interested in whether it will help reduce the number of trips to the bathroom at night for patients with Parkinson's disease. Because it helps the body hold on to water, it may also reduce morning postural light-headedness from low blood pressure.

We are looking for participants from the Brisbane metro area who have been diagnosed with postural hypotension by a doctor and have to urinate two or more times at night. Participants must also be able to keep a symptom diary. The study involves an initial screening visit. If you qualify, you will attend six 20-minute visits and three 1.5-hour visits over 10 weeks.

All participants will get desmopressin and placebo tablets during the trial, but they will not know what they are taking at any one time. There is no cost to you, and travel reimbursement will be provided. Please note that if your doctor does not work at the Royal Brisbane & Women's Hospital, your doctor must approve your enrolment in the trial and will still be responsible for your care during the trial. Enrolment is open now.

If interested, please contact Dr. Melinda Burnett
via phone: 0422 030 851,
or email: melinda_burnett@health.qld.gov.au



SEMINAR ANNOUNCEMENT Parkinson's Qld Inc.

invite you to hear

**PROFESSOR PETER SILBURN and
KAREN O'MALLEY – Nurse Consultant**

**Important Aspects of Parkinson's Disease
For Those Newly Diagnosed**

This seminar is targeted to people who have been diagnosed in the last 5 years, their families, carers and friends. Bookings are essential for planning purposes.

Please phone 1800 644 189 or (07) 3209 1588

**September 2nd, 2009
6 PM to 8 PM**

**At University of Qld Centre for Clinical Research
Royal Brisbane and Women's Campus**

There is a car park within 150m and public transport goes to the hospital.

*Every day may not be good, but
there's something good in every day.*

FROM AROUND THE GLOBE

The Lancet Neurology

Volume 8, Issue 5, Pages 464 - 474, May 2009

Non-Motor Symptoms of PD: dopaminergic pathophysiology and treatment

K Ray Chaudhuri DSc^{1,2} Anthony HV Schapira FMedSci³

Summary

Several studies, including work from the Parkinson's disease (PD) non-motor group and others, have established that the non-motor symptoms of PD are common, occur across all stages of PD, are under-reported, and are a key determinant of quality of life. Research suggests that the non-motor symptoms of the disease are frequently unrecognised by clinicians and remain untreated. Even when identified, there is a common perception that many of these symptoms are untreatable. The role of dopaminergic drugs in treating the various non-motor problems of PD, although clinically recognised, has received little attention.

In this Review, we investigate the dopaminergic basis of the range of non-motor symptoms that occur in PD such as depression, apathy, sleep disorders (including rapid-eye movement sleep behaviour disorder), and erectile dysfunction. We discuss the evidence that these symptoms are treatable, at least in part, with various dopaminergic strategies and, where relevant, we also refer to the use of deep-brain stimulation of appropriate targets in the brain. This Review provides a comprehensive overview of the management of this challenging aspect of PD.

¹ National Parkinson Foundation Centre of Excellence, King's College Hospital and University Hospital Lewisham, London, UK

² King's College and Institute of Psychiatry, London, UK

³ University Department of Clinical Neurosciences, Institute of Neurology, Queen Square, University College London, London, UK

More Attention To Non-Motor Manifestations of Parkinson's Disease

23 Jun 2009

An important problem of patients with PD is not related to dopamine deficit. "PD patients suffer not only of motor but also of such non-motor disturbances as sleep disturbances, depression, psychosis, hallucinations or dementia. These disturbances require a precise diagnostic work up and specific, usually non dopaminergic medications." A whole series of studies being presented at the ENS meeting are devoted to this problem area. This focus is important because non-motor manifestations may represent the first sign of PD, experts at the ENS meeting emphasize. From clinical, neuroimaging and pathological studies, evidence is in fact accumulating suggesting the onset of olfactory dysfunction, dysautonomia, mood and sleep disorders years to decades before the onset of motor manifestations of PD. "Epidemiological and clinical studies suggest that non-motor symptoms related to Parkinson disease may already occur a decade or two before motor manifestations begin," Professor Bassetti emphasizes. "And the neurodegenerative process could start years before these non motor symptoms make their appearance."

Source: **European Neurological Society**

Article URL: <http://www.medicalnewstoday.com/articles/154919>

Researchers Discover Possible Therapeutic Target to Slow Parkinson's Disease

Newswise — University of Medicine and Dentistry of New Jersey (UMDNJ) researchers have discovered a therapeutic target that, when manipulated, may slow the progression of or halt Parkinson's disease, a debilitating neuro-degenerative disorder that affects an estimated one million people in the United States.

A team from the Centre for Neurodegenerative and Neuro-immunologic Diseases in the Department of Neurology at the UMDNJ-Robert Wood Johnson Medical School carried out the study. M. Maral Mouradian, M.D., Centre Director and William Dow Lovett Professor of Neurology, was its lead investigator. A paper on their findings, titled "Repression of a-synuclein expression and toxicity by microRNA-7," appears in the July 20 edition of the *Proceedings of the National Academy of Sciences (PNAS)*.



In this publication, the investigators report that the small RNA molecule microRNA-7, which is present in neurons, directly represses the expression of a-synuclein, a protein that, in excess, proves deleterious to certain types of brain cells.

"Individuals who have multiple copies of the a-synuclein gene come down with Parkinson's, so inhibitors of a-synuclein expression are attractive therapeutic targets," explained Mouradian. "Our manipulation protects neuronal cells from the toxicity that results from increased levels of this protein."

There is no cure for Parkinson's and there are no neuroprotective treatments as of yet, making this new strategy to manipulate the molecular underpinnings of the disease a significant discovery, he added.

Source: University of Medicine and Dentistry of New Jersey

	<p style="text-align: center;">FOR SALE</p> <p style="text-align: center;">AS NEW SL-6 Lift Chair Comfort & Style Rarely used. Scotchguard Less than 1yo \$1000 o.n.o.</p> <p style="text-align: center;">Contact Mavis Edwards 07 3341 5227</p>
--	------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

EmaxHealth

Spinal Cord Stimulator Sparks Hope for Parkinson's Treatment

A novel stimulation method, the first potential therapy to target the spinal cord instead of the brain, may offer an effective and less invasive approach for Parkinson's disease treatment, according to pre-clinical data published in the journal *Science* by researchers at Duke University Medical Centre.

Researchers developed a prosthetic device that applies electrical stimulation to the dorsal column in the spinal cord, which is a main sensory pathway carrying tactile information from the body to the brain.

The device was attached to the surface of the spinal cord in mice and rats with depleted levels of the chemical dopamine — mimicking the biologic characteristics of someone with Parkinson's disease along with the impaired motor skills seen in advanced stages of the disease.

When the device was turned on, the dopamine-depleted animals' slow, stiff movements were replaced with the active behaviours of healthy mice and rats. Improved movement was typically observed within 3.35 seconds after stimulation.

"We see an almost immediate and dramatic change in the animal's ability to function when the device stimulates the spinal cord," says senior study investigator Miguel Nicolelis, MD, PhD, the Anne W. Deane Professor of Neuroscience at Duke.

"Moreover, it is easy to use, significantly less invasive than other alternatives to medication, such as deep brain stimulation, and has the potential for widespread use in conjunction with medications typically used to treat Parkinson's disease."

Researchers tested mice and rats with acute and chronic dopamine deficit using varying levels of electrical stimulation and in combination with different doses of dopamine replacement therapy, also known as 3,4-dihydroxy-L-phenylalanine or L-DOPA, to determine the most effective pairing.

When the device was used without additional medication, Parkinsonian animals were 26 times more active. When stimulation was coupled with medication, only two L-DOPA doses were needed to produce movement compared to five doses when the medication was used by itself.

"This work addresses an important need because people living with Parkinson's disease face a difficult reality - L-Dopa will eventually stop managing the symptoms," explains Romulo Fuentes, a postdoctoral fellow at Duke University and lead author of the study.

"Patients are left with few options for treatment, including electrical stimulation of the brain, which is appropriate for only a subset of patients."

While deep brain stimulation (DBS) and other experimental treatments attack the disease at its origin -- in the brain -- Nicolelis and team took a different approach. The concept for the device began when researchers made a surprising connection with another neurological condition.

"It was a moment of sudden insight," explains Nicolelis. "We were analysing the brain activity of mice with

Parkinson's disease and suddenly it reminded me of some research I'd done in the epilepsy field a decade earlier. The ideas began to flow from there."

The rhythmic brain activity in the animals with Parkinson's disease resembled the mild, continuous, low-frequency seizures that are seen in those with epilepsy.

One effective therapy for treating epilepsy involves stimulating the peripheral nerves, which facilitate communication between the spinal cord and the body. Researchers took that concept and developed a modified approach for a Parkinson's disease model.

Nicolelis says that the low frequency seizures, or oscillations, seen in the animal model of Parkinson's disease have been observed in humans with the condition. Stimulating the dorsal column of the spinal cord reduces these oscillations, which researchers believe creates the ability to produce motor function.

In a healthy body, neurons fire at varying rates as information is transmitted between the brain and the body to initiate normal movement. This process breaks down in someone with Parkinson's disease.

"Our device works as an interface with the brain to produce a neural state permissive for locomotion, facilitating immediate and dramatic recovery of movement," says Per Petersson, co-author of the study.

"Following stimulation, the neurons desynchronize, similar to the firing pattern that you would see when a healthy mouse is continuously moving."

Nicolelis says that if the device is proven safe and effective through further research, he imagines it mirroring similar spinal cord stimulator technology currently used to treat chronic pain.

Small leads are implanted over the spinal cord and then connected to a portable generator, a small device capable of producing mild electrical currents. During the trial period, the generator is external, while for permanent treatment it would be implanted below the skin.

"If we can demonstrate that the device is safe and effective over the long term in primates and then humans, virtually every patient could be eligible for this treatment in the near future," Nicolelis said.

The Duke team is collaborating with neuroscientists at the Edmond and Lily Safra International Institute of Neuroscience in Natal, Brazil, to test the new procedure in primate models of Parkinson's disease prior to initiating clinical studies.

Neuroscientists from the Brain and Mind Institute at the Swiss Institute of Technology (EPFL), in Lausanne, Switzerland, will also participate in this international research effort to translate these new findings into clinical practice.

Source: Duke University Health System

Man can live about forty days without food, about three days without water, about eight minutes without air ... but only for one second without hope.

— Hal Lindsey

Caring for the Carer

Being a carer is a stressful and demanding job. There is usually very little, if any, opportunity to prepare for a new care giving situation. The well-being of the carer requires priority consideration. Thought must be given to the fate of the care recipient if the carer becomes unable to continue with care giving responsibilities. Carers are susceptible to depression, illness, physical exhaustion and emotional exhaustion. Any of these conditions will easily interfere with a person's ability to be an effective carer.

The following are suggestions for maintaining carer well-being:

- Become informed about the care recipient's health issues and any expected changes in behaviour.
- Accept the facts and deal with your situation the best that you can.
- Seek professional help whenever necessary.
- Share the burden of caring and care giving with family members and other interested persons.
- Talk about your problems with a trusted person.
- Don't be too shy, proud, or afraid to seek help with care giving.
- Become aware of the limits of your care giving abilities.
- Maintain social activities and important relationships.
- Get away from the responsibilities from time to time.
- Pace yourself. You may be responsible for care giving for many years.
- Work off anger with physical activity.
- Plan ahead to avoid crises where possible.
- Live one day at a time.
- Recognize the worst-case scenario, but hope for the best.
- Join a family support group.
- Keep your sense of humour.

Taken from: "Understanding and caring for the person with Alzheimer's Disease" A Guide by the Alzheimer's Association.

You pass this way only once
so enjoy it while you can;
Live A Lot, Laugh A Lot and Love A Lot!

Volunteers Needed for Parkinson's Research

- ◆ Professor Silburn needs 5 or 6 right handed people with Parkinson's disease.
- ◆ They must not be on anti-depressants or anti-anxiety drugs.
- ◆ Not claustrophobic.
- ◆ Please contact on 07 3839 3688

Not everything that can be counted
counts, and not everything that counts
can be counted.

... Albert Einstein

YOUR CONTRIBUTION remains the most important – without you we would have empty pages. So please keep your articles, comments and input flowing ...

Anyone who has good quality new items that they don't want any more which could be used for raffles, could you please let the office know, and we can arrange a pick-up.

ADVERTISEMENT





**Your Trusted Non-Medical Source of
Companionship and Home Care**

Home Instead CAREGivers can help you live an independent lifestyle in your own home for as long as possible. From a few hours a day, up to 24 hours - seven days a week, including weekends and holidays - Home Instead CAREGivers can assist you with some or all of the following services:

• Personal Care	• Transport for Appointments, Shopping, Errands
• Companionship	• Respite & Convalescence Care
• Light Housekeeping	• Support for people living with Parkinson's
• Meal Preparation	
• Medication Reminders	

**All our CAREGivers are thoroughly screened, trained and insured.
Call for a free no-obligation consultation**

homeinstead.com.au

• Brisbane North (07) 3720 8400 • Brisbane South (07) 3277 3077
• Gold Coast (07) 5574 3286 • Caboolture (07) 3482 0800

MERCHANDISING

We are continuing to add to our merchandise for sale.

NEW Merchandise (not available yet)

- | | |
|--------------------------|-------------|
| 1. Water Bottle Carriers | \$2.00 each |
| 2. Mykonos Pens | \$3.00 each |

Just Arrived
Neoprene Wine
Coolers \$8.50 each



Parkinson's
Pens



Self-Help

In addition to the various treatment procedures, there are many things a person diagnosed with Parkinson's can do to help him/herself. While any and all treatments and therapies should be discussed with one's healthcare provider, the following may be of help:

Nutrition/Diet: Because it is believed that Parkinson's may be associated with free radicals (potentially damaging molecules produced in cells as part of cell activity or in response to injury), it is important to eat foods that contain antioxidants. Foods that contain antioxidants are fruits, vegetables and whole grains. A balanced diet that contains these can help protect against free radical damage. They are also high in fibre, which is important for the Parkinson's patients that suffer from constipation. Your healthcare provider may advise taking a fibre supplement, such as Metamucil, however, it should be introduced slowly and it is imperative to drink eight to ten glasses of water daily. Limiting caffeine and alcohol is also helpful. Reducing the consumption of fat, especially saturated fats can be helpful in maintaining an acceptable weight. Because Parkinson's disease slows gastric motility, swallowing is prolonged, and therefore food absorption is slower. Eating small amounts of food throughout the day is better for the Parkinson's patient than three large meals. If a Parkinson's patient is taking Sinemet, it should be taken on an empty stomach. Even taking it fifteen minutes before eating is preferable. If nausea is present, it may be taken with a non-dairy fluid and a small cracker, bite of fruit, even a pretzel. Ginger has been found to be helpful in offsetting nausea.

Taking Sinemet on an empty stomach allows it to be absorbed more easily and quickly. Some healthcare providers may recommend vitamin or antioxidant supplements. Talk to your healthcare provider about the benefit of adding these to your diet. Parkinson's patients often have trouble swallowing, especially in the latter stages of the disease, therefore it is important to remember to take small bites of food, chewing them completely and swallowing before taking another bite.

Chopping food in a food processor may also be helpful, as would using a plate warmer under the plate to insure the food doesn't get cold, thus allowing you to take your time in eating.

Exercise: Regular exercise is important for Parkinson's patients. It aids in mobility, balance, and range of motion. Your healthcare provider may recommend an exercise program for you, however, walking, swimming, and gardening have all proved beneficial. Studies have shown that activities such as walking, jogging, and even dancing may be more helpful than physical therapy. Making sure that your medicines are working well and you are feeling strong, as the energy level may go up and down, are important things to consider before beginning any exercise. In the case of fatigue, it may be helpful to do part of your exercise routine in the morning, and another part in the evening. Make sure and stretch before exercising as this helps to warm up the muscles and also helps to prevent stiffness. Stretching also improves balance and flexibility. Some healthcare providers are suggesting that their patients try Tai Chi, a Chinese form of exercise that uses slow, graceful movements to relax and strengthen the muscles and joints. It is also known

to be beneficial in improving balance. It is imperative to always consult with your healthcare provider before starting any exercise program.

Walking: Walking is difficult for the Parkinson's patients, especially in the latter stages due to the shuffling and foot drag that is common to this disease. Making sure to use proper posture and wearing the right shoes, such as a pair of good walking shoes can help. One of the problems that Parkinson's patients face is what is known as "freezing". This usually happens when a person with Parkinson's stops or tries to pivot in order to turn and their feet become "frozen" in place. Rocking gently from side to side, or pretending to step over an object on the floor can aid in this. Avoiding prolonged standing, using a large rubber tipped cane, using a forward facing wide U-turn rather than the usual pivoting and keeping distractions to a minimum can help the patient avoid falls. Also, standing with feet eight to ten inches apart instead of close together may be of help.

There are many products on the market that can help the people who have Parkinson's disease. These would include handrails (especially on staircases) and grab bars for around the tub and beside the toilet. Removing area rugs can also help.

Music Therapy: A therapy that uses music and rhythm to help improve the patient's mobility and balance has been used with some success. You can check with your healthcare provider to find this therapy in your area.

Dressing: As dressing can become an ordeal for a person who has Parkinson's disease, it might be helpful not only to allow plenty of time for dressing, but also to choose clothes that slip on easily or that have Velcro fasteners rather than buttons or zippers.

Speaking: A person who has Parkinson's disease often speaks with a soft or hoarse voice. In order to communicate more easily, face the person you are talking to and speak deliberately and more loudly than you think necessary. Reading or singing out loud while focusing on breathing aids in strengthening the vocal cords and the throat muscles which in turn aid in swallowing. Consulting with a speech pathologist that is trained to treat Parkinson's patients can also be beneficial.

Parkinson's disease is a progressive disease, and while none of these tips can eliminate or cure any of the problems associated with Parkinson's, making certain lifestyle changes can help make living with the disease easier.

The information in this or any article should never be used to diagnose oneself. If Parkinson's or any disease is suspected, a healthcare provider should be contacted as soon as is possible, in order to detect early symptoms and begin treatment.

The best time to start thinking about your retirement is before the boss does.

Improving Doctor / Carer Communications

There is much to be gained by improving communications between family carers and health care professionals, especially physicians. Positive outcomes include: better care for the patient, less stress and illness for the carer, more efficient use of doctors' time, reduced costs for the health care system, and more satisfaction for all concerned.

In order to reap these benefits family carers and physicians need to gain a better understanding of each other's worlds. Both need to try, as hard as it is, to "walk in each other's shoes".

The following guide is offered as a path for doing that.

Tips for Doctors from Family Carers

- Be open and forthright.
- Think about the practicality of the treatments you suggest and consider their effect on the entire family, not just their medical efficacy.
- When you prescribe medications, be sure carers understand potential side effects so they know what to expect.
- In non life threatening situations, assure carers that every decision doesn't have to be made on the spot. Respect the right of the carer and the patient to think things over.
- Now and then ask the carer: How are you? Let them know you understand that illness and disability are a family affair.
- Be accessible—especially when a carer is opening his or her heart.
- Reach out to the carer—literally. A simple touch can mean a great deal.

- Be sensitive about where you talk to carers about difficult subjects—waiting rooms and corridors are not appropriate.
- Always explain as completely as possible all of the legal ramifications of life-saving actions.
- Be prepared to point carers toward helpful resources. Living with a chronic illness or disability requires more than medicine has to offer.

Tips for Family Care Givers from Doctors

- Write questions down so you won't forget them.
- Be clear about what you want to say to the doctor. Try not to ramble.
- If you have lots of things to talk about, make a consultation appointment, so the doctor can allow enough time to meet with you in an unhurried way.
- Educate yourself about your loved one's disease or disability. With all the information on the Internet it is easier than ever before.
- Learn the routine at your doctor's office and/or the hospital so you can make the system work for you, not against you.
- Recognize that not all questions have answers—especially those beginning with "why."
- Separate your anger and sense of impotence about not being able to help your loved one as much as you would like from your feeling about the doctor. Remember, you are both on the same side.
- Appreciate what the doctor is doing to help and say thank you from time to time.

www.nfcacares.org



- **Monthly Payment Option Available**
- **Pensioner Discount**



Freecall: 1800 355 591

Fax: 46 136 199

Email: general@pmainsurance.com.au

30b Warwick Street, Toowoomba

Mail: PO Box 2912, Toowoomba Q 4350

(PMA General Pty Ltd t/as) AR 253903

The Good Old Days

Someone asked the other day, "What was your favourite fast food when you were growing up?"

"We didn't have fast food when I was growing up," I informed him. "All the food was slow."

"C'mon, seriously. Where did you eat?"

"It was a place called 'at home,'" I explained!



"Mum cooked every day and when Dad got home from work, we sat down together at the dining room table, and if I didn't like what she put on my plate I was allowed to sit there until I did like it."

By this time, the kid was laughing so hard I was afraid he was going to suffer serious internal damage, so I didn't tell him the part about how I had to have permission to leave the table.

But here are some other things I would have told him about my childhood if I figured his system could have handled it :

Some parents NEVER owned their own house, wore Levis, set foot on a golf course, travelled out of the country or had a credit card.

My parents never drove me to school. I had a bicycle that weighed probably 50 pounds, and had only one speed, slow.

We didn't have a television in our house until I was 19. It was, of course, black and white, and the station went off the air at midnight, after playing the national anthem and a poem about God; it came back on the air at about 6 a.m. and there was usually a locally produced news and farm show on, featuring local people.

I never had a telephone in my room. The only phone was on a party line. Before you could dial, you had to listen and make sure some people you didn't know weren't already using the line.



Pizzas were not delivered to our home. But milk was.

All newspapers were delivered by boys and all boys delivered newspapers — my brother delivered a newspaper, six days a week. He had to get up at 6 a.m. every morning.

Movie stars kissed with their mouths shut. At least, they did in the movies. There were no movie ratings because all movies were responsibly produced for everyone to enjoy viewing, without profanity or violence or most anything offensive.

If you grew up in a generation before there was fast food, you may want to share some of these memories with your children or grandchildren.

Just don't blame me if they bust a gut laughing.

Growing up just isn't what it used to be, is it?



Commonwealth Respite and Carelink Centre

The Commonwealth Respite and Carelink Centre (The Centre) assists people through provision of free information about aged care, disability and other community care services. The Centres have a local knowledge about a range of services available and how to contact them including:

- household assistance,
- personal, nursing and respite care,
- transport and meal services,
- assessment services,
- continence assistance to name a few.

The Centres can also assist carers who provide significant time to care for someone, such as a husband, wife, son, daughter, grandparent or friend. The person cared for may be frail aged, a person who has dementia, an adult or child with a disability or a person with a chronic illness, a mental illness or is in need of palliative care.

Respite means taking a well-deserved break from your caring role. Respite can be provided in a variety of settings including in the home, within a centre or residential care facility or in the community.

The Centres can provide:

- Information about respite care,
- Referrals to appropriate service,
- Funding for respite care in emergency or short term planned care situations,
- Assistance in locating residential respite,
- Access 24 hours a day for emergency respite service.

Freecall TM1800 052 222*

*Calls from mobile phones are charged at applicable rates.

LSVT - GLOBAL

Earlier this month I attended a LSVT-LOUD symposium for people with Parkinson's disease. Presented by Professor Deborah Theodoros, this informative lecture in speech treatment for those people with PD who were having difficulty with their speech.

The lecture was presented in a light-hearted manner discussing the principles of LSVT to intensive whole body amplitude-based training protocol for individuals

A key component of this treatment is exercise, practice. Practising the skills taught with 'daily tasks' including repetitions of voice exercises.

An interactive session followed the lecture where those with PD received individual LSVT-LOUD treatment from speech therapists who were in attendance.

LSVT-GLOBAL now encompasses the LOUD program and LSVT-BIG (big movements) which is a novel integrated treatment that retrains normal use of voice and movement. This may also help with dual-tasking.

"Your future depends on your dreams" So go to sleep!

From **'Masterchef' Kitchen**

Beef and Noodles

(Lunch or Dinner)

Ingredients

- 500g ground beef
- 1bag of noodles
- garlic
- onion
- olive oil
- 1bag mixed vegetables
- season salt or salt to taste
- optional 1can tomato sauce



Preparation time: 1 hour

Number of servings: 4-6

Instructions:

Ground beef, garlic, onion and noodles in olive oil, until brown. Remove excess oil add mix vegetables. Season with salt. Add tomato sauce and simmer covered for 20-30 minutes.

Diet condition: Substitute oil, no salt or substitute

Ode to Parkinson's

I thought I was beginning to no longer care,
 Where is the life, we used to share?
 How did it happen, where did it go?
 All of the loving we used to know!
 Love is forever, love never dies,
 and love never lies!
 I know we can go on to open the door,
 to our hearts, and love once more!
 Then come let me love you!
 Come kiss me today,
 and we shall go on together,
 to find "Yesterday"

Alan Gray, Buddina

And a note from John Butcher in Malanda.

"Well, goodbye Bill, let's shake hands.
 Other people talk about it but we actually do it"
 "There is an integrity about sufferers of Parkinson's
 — a certain honesty. Other people talk about
 shaking hands but we actually do it"

The children were lined up in the cafeteria of a Catholic elementary school for lunch. At the head of the table was a large pile of apples.

The nun made a note, and posted on the apple tray:

"Take only ONE. God is watching."

Moving further along the lunch line, at the other end of the table was a large pile of chocolate chip cookies.

A child had written a note, "Take all you want. God is watching the apples."



Doctor, Doctor! I have a serious problem,
 I can never remember what I just said.
 When did you first notice this problem?
 What problem?

A truck driver is stuck under bridge and cars are backed up for miles. Finally, a police car comes up.

The cop gets out of his car and walks around to the truck driver, puts his hands on his hips and says, "Got stuck, huh?"

The truck driver says, "No, I was delivering this bridge and ran out of gas."

Three men were hiking through a forest when they came upon a large raging, violent river.

Needing to get to the other side, the first man prayed: 'God, please give me the strength to cross the river.'

Poof! ... God gave him big arms and strong legs and he was able to swim across in about two hours, having almost drowned twice.

After witnessing that, the second man prayed: 'God, please give me strength and the tools to cross the river' Poof! ... God gave him a rowboat and strong arms and strong legs and he was able to row across in about an hour after almost capsizing once.

Seeing what happened to the first two men, the third man prayed: 'God, please give me the strength, the tools and the intelligence to cross the river.'

Poof! ... He was turned into a woman. She checked the map, hiked 100 metres upstream and walked across the bridge.

Moral: 'If at first you don't succeed, do it the way your wife told you to.'



Suppliers of specialised clothing to both Nursing Homes & the public.

Men's & Women's clothing & sleepwear including:

- Back opening garments
- Pull-on Pants & Skirts
- Men's satin Pyjamas
- Leg/Arm Protectors
- All-In-One Suits
- Arcopedico Shoes
- Satin insert fitted sheets*

*Parkinson's WA purchase our sheets for their members. Available in sizes Single through to King. Order forms for Satin Insert Sheets & Satin Pyjamas available from Parkinson's QLD. or by contacting Easywear.

Suite 1/15 Howe St, Osborne Park WA 6017 T: 08 9445 2333 • F: 08 9445 2311
 E: info@easywearaustralia.com.au • Website: www.easywearaustralia.com.au




Phone for our free catalogue

Parkinson's Queensland Inc.**NOTICE OF ANNUAL GENERAL MEETING**

Notice is hereby given that the Annual General Meeting will be held on 12 September 2009

Venue: Logan Uniting Church –
Yurana Activity Hall
129 Dennis Rd,
Springwood Qld 4127

Time: 10.30am to 12.30pm

Registrations: 10.00am

Items of Business

- Adoption of minutes of the AGM held 15 November 2008
- Business arising from the minutes
- President's Report
- AMENDMENTS TO PQI CONSTITUTION
- Report of Audited accounts
- Guest Lecture

Voting rights on motions put to the meeting are as defined in clauses 24.4 and 24.6 of our constitution.

Parkinson's Qld Inc. Support Groups

			Day	Time	Where
Broadbeach Group	Kevin Robins	3807 0228	3rd Wed	10:00am	Clear Island Waters
Mt Gravatt Group	Mavis Edwards	3341 5227	4th Mon	10:00am	Mt Gravatt
QYPP Group	Kevin Robins	3807 0228	2nd Tue	10:30am	Mt Gravatt
Logan Group	Margaret Vickers	3808 6356	1st Tue	10:00am	Loganholme
Carer's Group		3209 1588	1st Thu	10:00am	Springwood
Redlands Group	Phyllis Trost	3207 4664	3rd Thu	10:00am	Cleveland
Mitchelton Group	David Martin	3410 8054	1st Tue	10:00am	Mitchelton
Kedron Group	Pam Furner	5499 3890	3rd Sat	2:00pm	Kedron
Indooroopilly Group	Ann White	3878 9433	2nd Sat	10:00am	Indooroopilly
Western Suburbs	Jocelyn Wilson	3378 1474	1st Mon	2:00pm	Sinnamon Park
Ipswich Group	Di Bergman	3817 2361	2nd Tue	10:00am	Ipswich
DBS Group	Judy Rawlins	3886 1592	Phone Only		All Queensland
Warwick Group	Patsy Slater	4661 4566	2nd Thu	1:30pm	Warwick
Toowoomba Group	Delia Sharp	4696 8734	1st Thu	10:00am	Toowoomba
Caboolture Group	Joy Boyle	5498 7333	3rd Wed	12:00pm	Caboolture
Nambour & Districts	Daphne Roberts	5445 0528	Last Fri	9:30am	Nambour
Tewantin/Noosa	Joan & Pat Murray	5442 4110	2nd Fri	9:30am	Noosaville
Maryborough Group	Gail Wixon	4123 3407	1st Wed	2:00pm	Maryborough
Bundaberg Group	Elaine Williams	4159 8118	3rd Mon	10:00am	Bundaberg
Rockhampton Group	Jan Nolan	4928 5863	3rd Wed	10:00am	Rockhampton
Mackay Group	Diane Phelan	4942 0632	3rd Thu	10:00am	Mackay

Please be aware that co-ordinators with Parkinson's make take some time to answer the phone.

We are in the process of commencing another support group in the Mareeba district of Far North Qld. If there's anyone interested in this group could you please contact Mr 'Slim' Pearsall - 07 4092 1374

The wise never marry, and when they marry they become otherwise.

THANK YOU TO THOSE WHO HAVE GENEROUSLY DONATED TO PARKINSON'S QLD INC IN THE MONTHS TO AUGUST 2009. ALTHOUGH WE CANNOT LIST ALL YOUR NAMES, YOUR SUPPORT IS GRATEFULLY RECEIVED. LISTED ARE THOSE WHO KINDLY DONATED \$50 OR MORE.

DONATIONS: J&G ANDERSON, A BALATONACZ, G&K BIRD, A BOND, G BROCK, K BROTHERS, D&M BROWN, J BROWN, L CALLON, E CAMPBELL, J COLWILL, M DOWNES, I&D FRITZ, E GAROZZO, G HAVIG, R HODGSON, C JACKSON, ESTATE VERA KENDALL, J KINCADE, J KNOBLAUCH, P KORNAOOHOFF, J LAMBERT, C LANNING, S LEWIS, BC MANN, J McINTYRE, T McINTYRE, N McLEOD, V MEIER, GK NEWMAN, N PETERSEN, ALWYN PEPPER & CO, P&P POHLNER, F POLLOCK, M ROBSON, N&A RUSSELL, N RUSSELL, P SAUNDERS, C SCHMIDT, E SHAXSON, Dr SPAIN, G STEVENS, E STEWART, K STOLLZNOW, R TOON, A VAN KLINKEN, S VOSS, S WATTS, R&J WEIS, A WHITE, M WOLLERT.

IN MEMORY. WE GREATLY APPRECIATE ALL THE GIFTS WE HAVE RECEIVED IN MEMORY OF LOVED ONES. THOSE REMEMBERED HERE ARE: KEN BUDDEN, DESMOND CAMPBELL, DAWN CLARKE, BERYL GRAHAM, KEVIN GREEN, PATRICIA GROSS, BETTY LESTER, EVELYN MILLARD, JOHN SHERRIFF, PETER SIMS, KEITH STOLLZNOW, KEN SUMMERS, ERROL WILFRED,

Deadline for contributions to the Summer Quarterly issue is November 18th