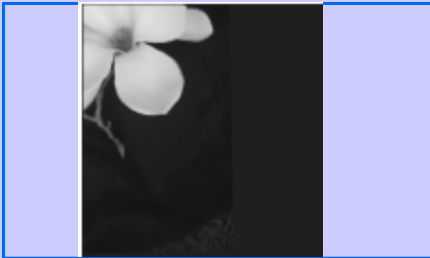


December 2010



**Honorary Medical Advisor:**  
Assoc. Prof. David Williams.  
MBBS, PhD, FRACP.

**Key contacts PSP Australia**  
Anne Mooney (Convenor)  
Ph: (03) 9568 7748  
[damooney@bigpond.com](mailto:damooney@bigpond.com)

Shirley Milne  
Ph: (03) 9503 9057  
[glaciarium@optusnet.com.au](mailto:glaciarium@optusnet.com.au)

**Telephone Support:**  
Melbourne Area  
Anne Mooney: (as above)

Shirley Milne: (as above)

**Country Victoria**  
Bruce Eva  
(03) 5853 1006

Pam Collins  
(03) 5472 2783

**New South Wales**  
Alice McPherson  
(02) 4421 5202

Kate Blizzard  
0412 534 908

Claudia Berry:  
(02) 9997 3927

**Website**  
[www.psp-australia.org.au](http://www.psp-australia.org.au)

Address for correspondence:  
PSP Australia,  
C/- 5/15 Heath Avenue  
OAKLEIGH VIC 3166

**Minutes from PSP Australia/Support Group Meeting:**

**Thursday 2nd December 2010**

**Present:**

We had 14 members present, all contributing to a very informative meeting.

A very warm welcome was extended to Alice and her friend Peg who journeyed down from NSW

**Apologies:**

Muriel and Bruce Kendall, Doreen Barr, Yvonne Murphy, Robert and Jill Botherill

**In Memoriam:**

Our thoughts and prayers are extended to:

James Kavanagh whose wife, Josette, lost her fight with PSP.

Paula Lepore lost her dad from complications caused by PSP.

Delia Latimer lost her husband Bill to pneumonia.

**Correspondence in:**

Nil

**Correspondence out:**

Nil

**Donations:**

We are grateful for the following donations:

In memory of Bill Latimer: \$75.00

Artarmon Public School: \$100.00

In memory of Ross Moffat: \$270.00

**Accounts paid:**

Affinity Press: \$517.00

Hall hire: \$44.00

Parkinsons Vic: \$1000.00

**New Members:**

We extend a warm welcome to our new members:

Jill Sole from Skye

William & Hazel Trant from

Avondale Heights

Yvonne Haxton from Broadmeadows

Our **guest speaker** for our February meeting is Movement Disorders Nurse Victor McConvey from Parkinson's Victoria. Victor has extensive knowledge in the care of the person with PSP and the impact PSP has on the patient, carer and family. Please gather all your questions and come along to our meeting and have them answered.



**May all of our members and their families have a Truly Magical Christmas filled with Loving Wishes and Beautiful Thoughts, May 2011 mark the beginning of a Tidal Wave of Love, Happiness, Bright Futures and Contentment**



**MINUTES OF PSP MEETING HELD ON THURSDAY 2ND. DECEMBER**

*PRESENT: Llwyd & Cheryl Jones, Gayle Williams, Karen Syms, Lesley Scanlon, Margaret Terry, Shelley Pollak - Physio - Parkinsons Vic., Anne Mooney, Michelle Wootton -Client Services - Parkinsons Vic., Alice Mc Pherson, Shirley Milne, Peggie Meredith, Keith & Ann Robinson*

*We welcomed Shelley Pollak - Physiotherapist & Michelle Wootton - Client Services from Parkinson's Victoria. Shelley has 7 - 8 years experience in Physiotherapy & spoke about the various items listed below to help PSP patients.*

*A heavy walking frame is best to help prevent falling backwards.*

*Make sure there is nothing loose on the floor (eg: rugs) & no distractions whilst walking*

*Hip protectors are very useful and their use is under emphasized in helping to prevent broken hips from falls.*

*Try to keep things that a person uses a lot within easy visual reach so they don't have to stretch to reach items. This might help to prevent falling.*

**CHEST INFECTIONS:**

*Encourage careful swallowing & sitting in an upright position.*

*To help keep the lungs clear - deep breathing & coughing exercises encouraged.*

*Take a deep breath & hold it to fill the lungs - you should feel the air expand the sides of the chest.*

*Repeat 5 times.*

*Then follow with a huff & a cough.*

*Hopefully this will help to clear the lungs.*

**STIFFNESS & PRESSURE SORES**

*It isn't good for a person to sit for long periods of time without moving— if watching T.V. get them to move in the add breaks. Get up & walk around, even standing up & sitting down a few times helps.*

*Don't stay in the same position for more than 1 hour*

*A pressure cushion is very good to use.*

*A massage is very beneficial using a moisturizer (eg: sorbolene) or almond oil. It is a nice personal touch with the person you are caring for.*

**GOOD EXERCISES TO HELP WITH STIFFNESS****ARMS**

*-Whilst sitting on a chair, hold onto the back of the chair with both hands, lean forward \* straighten arms. Hold 30 seconds - repeat several times.*

*-Whilst sitting upright on a chair, put hand behind neck & raise elbow to feel the pull - hold 30 seconds. Repeat several times & then do the same with the other arm*

*-Whilst sitting on a chair put arm upright in the air & bend sideways over towards the other side of the body. You should feel the pull down the side on the upright arm. Hold 30 seconds - repeat several times & then do the same with the other arm.*

**NECK - DON'T HOLD for 30 seconds**

Do these exercises sitting on a chair with your hands down by your side , not on your lap - this helps to lower your shoulders & you get a better stretch.

-Turn the neck sideways as far as you can to feel a stretch & then turn the other way to do the same.

-Tilt the head down so the ear goes towards the shoulder & you feel a pull.

Repeat with the other side.

**HAMSTRINGS**

-Sit on a chair & lean forward. Straighten leg & tilt toes upwards & hold for 30 seconds. - repeat several times & then do with the other leg.

A towel can be used under the foot & pulled upwards with the hands if needed or some-one can assist.

**CALF MUSCLES**

-Whilst sitting on a chair with leg either bent or straight, put a towel under foot & pull up to stretch. This gives both muscles in leg a stretch, but if not comfortable do whatever suits you best. This is similar to "hamstring" stretch, but not sitting forward on chair.

**BACK STRETCHES WHILST LYING IN BED**

-Whilst lying in bed with knees bent - slowly roll knees side to side - good for lower back stretch.

-Whilst lying on back with arms out to side, reach one arm over towards the other arm & then change arms. This is a good stretch for the high back muscles.

**QUESTIONS ASKED TO SHELLEY:**

-To help a stiff neck - put heat pack on neck followed by a neck rub..

-To help clear mucus - sit person upright & do cupping on their back whilst sitting behind them.

Contacting some-one who specialises in this can be helpful to show different technique procedures.

**GENERAL DISCUSSION:**

-A Conference for Carers will be held in February - date & place to be confirmed.

-Photos showing the correct procedure to get a person up from the floor after a fall to be included in newsletter.

-Alice McPherson from N.S.W. spoke about a phone linkage that has been set up .

Every 2 months a phone hook up is set up for an hour where people can ask questions & talk to each other about PSP problems. The teleconference started out with about 12 people and now has about 26 people participating. It has been found to be very beneficial to both longer diagnosed patients & carers as well as new people wanting information about " PSP".

-Also mentioned was that in N.S.W they have a nurse from Parkinson's who specializes in PSP, CBD & MSA. They are hoping to get funding from the Government for another specialized nurse.

## Round the table chat:

*Please be aware that all hints and advice contained in this newsletter should be referred to your own doctor or health worker.*

*As we know, every PSP sufferer responds to different treatments in different ways.*

*The following hints have appeared in previous editions of our newsletter but have been included again for the information of our newer members.*

### **Conversations:**

#### **Person with PSP**

*Encourage them to provide enough information when talking.*

*Say the main points.*

*Look at the person: Expression*

*HAVE THEY UNDERSTOOD YOU?*

*DO YOU NEED TO GIVE MORE INFO?*

*Give a little more information*

*Tell the listener that you are having trouble putting the sentence together. ie: Don't withdraw, tell the listener "I'm having a seniors moment" (lightens the conversation)*

#### **LISTENER**

*Clarification requests.*

*Clarify the main/common referent: ie: Are we discussing the toaster or the blue box*

*Remember to ask*

*WHAT, WHO, WHERE, WHEN and WHY*

### **Procedure for airway management of swallowing impaired patients**

*1, Sit upright*

*2, Encourage a cough to clear airway*

*3, Check patients mouth and clear any food*

*4, Deliver back blows 2-4 times between shoulder blades using heel of hand*

### **.Whilst drinking the following pattern is recommended**

*Sip*

*Hold*

*Chin down/Look at knees*

*Strong swallow*

**Tablets:** *coat in pureed fruit or jam*

**Foods:** *moist, soft, easy chew foods, coated in sauce or gravy.*

*Creamed soups*

**Fluids:** *if thin, use strategy as above. Try slightly thicker drinks such as apricot nectar*

### **THOUGHT FOR THE DAY**

**Be sure to**

**Cultivate**

**Positive**

**Thinking**

**For the right**

**Reasons:**

**To enhance the**

**Quality**

**Of your**

**Life**

**And the lives**

**Of others**

The following was sent to us from CurePSP in USA. website: <http://bit.ly/febCVA>

### Progressive Supranuclear Palsy and Dental Hygiene

Cynthia L. MacDonald, RDH

Progressive supranuclear palsy (PSP) may appear on a patient's health history; however, many dental team members may not understand the disease or the importance of working within the potential limitations that may accompany it. The purpose of this article is twofold: first, to identify and promote awareness of PSP, and second, to educate and share knowledge about how to provide treatment to these patients.

You may recall that the comic actor and acclaimed concert pianist Dudley Moore was afflicted with this disease. As a dental hygienist, I have encountered two patients diagnosed with PSP, and I also have more than 10 years of personal knowledge since this fatal disease is responsible for ending my mother's life.

PSP is a sporadic, progressive, neurodegenerative brain disease which affects nerve cells that control walking, balance, mobility, vision, speech, and swallowing. Five to six people per 100,000 will develop PSP, similar to the numbers of those diagnosed with Motor Neurone disease. In its early stages of gait disorder, PSP is most often diagnosed as Parkinson's or a "Parkinsonian" disorder. PSP is identified later through progressive symptoms.

On average, PSP begins between 40 and 60 years of age and has no known geographic, occupational, or racial preference. Clinical studies and research around the world show there is a clumping of Tau proteins in the cortical and sub cortical areas of the brain. Currently there is no effective treatment, medication, or cure, and aspiration pneumonia is usually the final cause of death.

As PSP progresses weakening muscles in the mouth, tongue, and throat, making the input of a Speech Pathologist important. If the person living with PSP requires a dentist it is critical that the dental practitioner be aware of the Diagnoses and its input on swallow and saliva management.

As the pharyngeal and tongue muscles alter with the progression of PSP the risk of Aspiration increases. The person living with PSP may experience coughing episodes or have a very slow and difficult swallow. It is at this point seeing a Speech Pathologist becomes very important and often recommendations of a safe seating position and consistency of meals and fluid. To help promote Oral Hygiene seeing a dental hygienist may be of benefit to aid in reducing oral bacteria. The Dental Hygienist may work in collaboration with the Speech Pathologist who will be able to provide information to assist in reducing the risk of aspiration and in managing the often tight jaw and facial muscles. The Speech Pathologist or Dental Hygienist will also be important in establishing a safe oral hygiene plan for the person living with PSP, family and carers to use

Some additional recommendations to aid in home care should include the use of a power toothbrush and a non-alcohol mouth rinse such as Biotene, which can often be used to swab the mouth.

A moist oral environment encourages easier swallowing and will help minimize the buildup of thickened and ropery secretions. To get the most effective management of secretions seeing a Speech pathologist is important. A Speech Pathologist will be able to recommend foods to avoid (E.g. some dairy products cause secretions to become thick and sticky) and the best ways of managing secretions.

It is important for Therapists' and health care professionals coming onto contact with people with PSP understand that although a patient's eyes may give the appearance of being disengaged, PSP DOES NOT impair the patient's ability to understand and comprehend. Encouraging health care professionals to ask direct questions that require yes or no answers will make it easier for people with PSP to respond, while allowing them to keep their dignity intact.

*This valuable information by Cynthia L. MacDonald, RDH first appeared in the CURE PSP newsletter in the United States in October 2010 and has been adapted to the Australian Health care environment.*



## PSP Notice board: News, Events, Updates

**PSP Australia is pleased to announce that it now has its own YouTube Channel where videos can be watched from your personal computer—whenever you choose!**

**YouTube** is a public website that allows users to post and share videos and resources, footage and information from around the world can watched for free.

Currently, the PSP Australia Channel features the main presentations from last year's **PSP Allied Health Professionals Day**.

This will be a wonderful resource for health professionals involved in the care of people living with PSP. They will be able to access this valuable information from anywhere in Australia, at their own time, and from their own workplace – for free!

The PSP Australia Channel can be accessed in 3 ways:

1. Direct by typing [www.youtube.com/australiapsp](http://www.youtube.com/australiapsp) into your browser
2. Go to YouTube ([www.youtube.com](http://www.youtube.com)) and then type in 'PSP Australia' into the search box
3. Go to PSP Australia ([www.psp-australia](http://www.psp-australia)) and click on the link/icon to the PSP TV page (available shortly)

Keep an eye on the PSP TV channel as more and more resources are made available and spread the word.

*Important note: As with any information posted on the internet, YouTube features videos uploaded by anyone and everyone, so we encourage you to be careful of what you watch and stick to material posted by reputable organisations.*

**PSP Australia** contact details:  
[www.psp-australia.org.au](http://www.psp-australia.org.au)

**Cure PSP (USA)** contact details:  
[www.curepsp.org](http://www.curepsp.org)

**PSP UK** contact details:  
[www.pspeur.org](http://www.pspeur.org)

**PSP France** contact details:  
[www.pspfrance.org](http://www.pspfrance.org)

**MSA Holland** contact details:  
[www.msa-ams.be@gmail.com](mailto:www.msa-ams.be@gmail.com)

PSP UK founder Brigadier Michael Koe has written a book detailing how he started the Association in the UK.

The book is called “Charity Begins At Home” and is full of hints that will enable us to further grow our own group. The book is a wonderful read and I have enquired into purchasing some copies for our members should anyone like to buy a copy.

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### Next Meeting

The date for our first meeting in 2011 is:

Thursday 3rd February

Time: 10.30

Address: Temple Society,  
152 Tucker Rd  
Bentleigh.

The cost per book is \$24.50. If anyone would like a copy please contact Anne Mooney on 03 9568 7748 or [damooney@bigpond.com](mailto:damooney@bigpond.com)

Orders are coming in so if you would like to purchase this excellent book please contact Anne to enable one shipment and therefore minimize postage costs.

### For the Calendar

Seminar date????

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We have a new nebulizer that has been kindly donated by Tania (David Williams secretary). and a bed pole. Should any one like to borrow either of these items please contact Anne Mooney on 9568 7748

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Enclosed is a Community Card that may be used at IGA and Ritchies Supermarkets. Cheryl Jones has kindly organized with the company that a percentage of monies spent in these stores will be donated to PSP Australia. And don't forget that you only have to spend \$25.00 to receive a saving on your petrol. Well done Cheryl!

**What is a “Webinar”?** Web conferencing is used to conduct live meetings, training, or presentations, via the Internet. In a web conference, each participant sits at his or her own computer and is connected to other participants via the internet. A **webinar** describes a specific type of web conference. It is typically one-way, from the speaker to the audience with limited audience interaction.

■ New members are warmly welcomed. If you would like to come along to a meeting, visit our website, or speak to a carer, our contact details are listed on the front page.

#### **Next Meeting:**

Our next meeting will be on Thursday, 3rd Feb 2011 at 10.30am at our new venue - see below

#### **PLEASE BE ADVISED**

Support Group meetings take place on the **first Thursday of every second month.**

Scheduled meeting times for 2011 are as follows:

- 3 February
- 7 April
- 2 June
- 4 August
- 6 October
- 1 December

#### **Venue**

Temple Society  
152 Tucker Rd  
Bentleigh Vic

#### **Time**

10.30am

We hope to see as many familiar and new faces as possible.

If you are unable to attend, you are welcome to contact us with any thoughts, stories or queries which may be included in our next newsletter.

## **Newsletter contributions Welcome**

Contributions for inclusion in the ***PSP Australia Newsletter*** are welcome and we encourage and invite anyone with a story, poem or comment to **post or email** it to ***PSP Australia*** (contact details on the back of this edition). This

ensures the newsletter represents all members of our community.

Please ensure you provide your contact details (name and phone number/email address). Articles can be featured anonymously on request.

We especially welcome contributions from members who are unable to attend ***PSP Australia Support Group*** meetings in the hope that, by contributing and 'having their voice heard', they will continue to feel they are a part of our community.

The following was sent to us from one of our members. It is certainly something to think about.

### **Crabby Old Man**

**When an old man died in the geriatric ward of a nursing home in North Platte, Nebraska, it was believed that he had nothing left of any value.**

**Later, when the nurses were going through his meager possessions, they found this poem. Its quality and content so impressed the staff that copies were made and distributed to every nurse in the hospital. One nurse took her copy to Missouri .**

**The old man's sole bequest to posterity has since appeared in the Christmas edition of the News Magazine of the St. Louis Association for Mental Health. A slide presentation has also been made based on his simple, but eloquent, poem.**

**And this little old man, with nothing left to give to the world, is now the author of this 'anonymous' poem winging across the Internet.**

**PTO**

*What do you see nurses? . . . . . What do you see?  
What are you thinking . . . . . when you're looking at me?  
A crabby old man . . . . . not very wise,  
Uncertain of habit . . . . . with faraway eyes?*

*Who dribbles his food . . . . . and makes no reply.  
When you say in a loud voice . . . . . 'I do wish you'd try!'  
Who seems not to notice . . . . . the things that you do.  
And forever is losing . . . . . A sock or shoe?*

*Who, resisting or not . . . . . lets you do as you will,  
With bathing and feeding . . . . . The long day to fill?  
Is that what you're thinking? . . . . . Is that what you see?  
Then open your eyes, nurse . . . . . you're not looking at me.*

*I'll tell you who I am. . . . . As I sit here so still,  
As I do at your bidding, . . . . . as I eat at your will.  
I'm a small child of Ten . . . . . with a father and mother,  
Brothers and sisters . . . . . who love one another.*

*A young boy of Sixteen . . . . . with wings on his feet.  
Dreaming that soon now . . . . . a lover he'll meet.  
A groom soon at Twenty . . . . . my heart gives a leap.  
Remembering, the vows . . . . . that I promised to keep.*

*At Twenty-Five, now . . . . . I have young of my own.  
Who need me to guide . . . . . And a secure happy home.  
A man of Thirty . . . . . My young now grown fast,  
Bound to each other . . . . . With ties that should last.*

*At Forty, my young sons . . . . . have grown and are gone,  
But my woman's beside me . . . . . to see I don't mourn.  
At Fifty, once more, babies play 'round my knee,  
Again, we know children . . . . . My loved one and me.*

*Dark days are upon me . . . . . my wife is now dead.  
I look at the future . . . . . shudder with dread.  
For my young are all rearing . . . . . young of their own.  
And I think of the years . . . . . and the love that I've known.*

*I'm now an old man . . . . . and nature is cruel.  
Tis jest to make old age . . . . . look like a fool.  
The body, it crumbles . . . . . grace and vigor, depart.  
There is now a stone . . . . . where I once had a heart.*

*But inside this old carcass . . . . . a young guy still dwells,  
And now and again . . . . . my battered heart swells.  
I remember the joys . . . . . I remember the pain.  
And I'm loving and living . . . . . life over again.*

*I think of the years, all too few . . . . . gone too fast.  
And accept the stark fact . . . . . that nothing can last.  
So open your eyes, people . . . . . open and see.  
Not a crabby old man . . . . . Look closer . . . . . see ME!!*