PARKINSON’S DISEASE

Parkinson’s disease is a progressive disease that affects an area in the brain called the Basal Ganglia. The Basal Ganglia controls body movements. Parkinson’s Disease is degenerative and principally effects movements. Other areas of the person’s life however, may be affected. For example concentration and memory may become worse over time.

Cause:

Although it is known that Parkinson’s disease affects the cells of the Basal Ganglia the exact cause of degeneration is not known. Two theories are that environmental toxins or genetic factors could be involved.

Prevalence:

Parkinson’s Disease affects people all around the world. It mostly affects people in the over the fifty age group. A study (by Mutch et al. 1986) has estimated that 1:1000 people over fifty get Parkinson’s disease, whereas the people over the 65 age group get Parkinson’s disease at a rate of 1:100. This statistic implies that the prevalence increases as the age increases. Parkinson’s disease affects more men than women.

Symptoms:

There are many symptoms of Parkinson’s disease. The four main symptoms are:

- Tremour in the hands, arms, legs, jaw and face.
- Stiffness, particularly in the trunk, but also in the arms and legs.
- Movement difficulties: initiating (starting) movements, slowness of movement and turning.
- Decreased balance and coordination.

Other symptoms of Parkinson’s disease are:

Problems seeing, sleep disturbance, difficulty swallowing, deficits in learning and remembering, slowness in thinking, decreased ability to take on too much information at any one time, difficulty getting words out or speaking softly, anxiety, depression, hallucinations and delusions.

People with Parkinson’s disease will not display all of these symptoms.

Movement:

People with Parkinson’s disease have difficulties starting to walk and they tend to walk slowly with shuffling steps. Often the swing of the arms is decreased in walking and the trunk is bent forwards. The reduction in speed and amount of movement can contribute to difficulties with balance, particularly if someone bumps the person while they are walking.
People with Parkinson’s disease are also likely to lose their balance if they have to turn abruptly or turn in a small circle.

Concentration is required to walk effectively, therefore people with Parkinson’s disease will not walk well if they are also doing something else, eg carrying things in their arms, holding a conversation, looking for something in the environment around them.

**Tremour:**

The cause of tremour is not known. Tremour is worse upon resting than upon purposeful movement.

**Seeing:**

Some people with Parkinson’s disease have difficulties with vision. Problems with vision include: reading, blurred vision, and difficulty following moving objects.

Before treatment, some people experience difficulties with blinking because their eye lid movement is slow and rigid. This can cause the eye to be teary. Absence of blinking can cause the person to stare or to look startled.

Prior to treatment, reading can be difficult due to decreased ability to perceive contrasting colours. Slow eye movement can cause difficulty with scanning (moving the eyes across the page) which is the movement required for reading. Slow movement of the eye also inhibits visually following moving objects.

Blurred vision may be due to slow eye movements causing a decreased ability to distinguish objects of similar colours, shapes, or sizes. Blurred vision may also be a side effect of medications for Parkinson’s disease.

**Sleep Disturbance:**

There are many reasons for sleep disturbance. Two reasons may be that the person has difficulty remaining asleep at night. The other is excessive daytime sleepiness. Some people may find it difficult to stay awake when doing quiet activities. If the need to sleep is severe however, it is possible that the person can fall asleep whilst doing active tasks.

Sleep disruption in Parkinson’s disease may be due to secondary causes such as depression.

**Swallowing:**

Difficulty swallowing may occur in Parkinson’s disease. The person may find it more difficult to swallow when they are eating if someone is talking to them, than when they are concentrating on swallowing only. In social occasions, such as meals, swallowing may need to be done in between conversation
turns. If the other people at the table are aware and mindful of this, being able to swallow and enjoy the company of others is likely to be facilitated.

**Depression:**

It is thought that people with Parkinson’s disease may be more at risk of developing depression than the general population.

People with depression and Parkinson’s disease have different symptoms than people with depression only. These symptoms include more anxiety, sadness without guilt or self blame and lower suicide rates despite high rates of suicidal thoughts.

Depression can add to the difficulties of every day life. It can cause a loss of interest in previously enjoyed activities, a sense of decreased energy, restlessness and irritability.

**Anxiety:**

Anxiety is common in Parkinson’s disease. It manifests itself with constant or episodic feelings of fear, worrying, and physical symptoms such as muscle tension, palpitations, sweating and shortness of breath.

Anxiety often accompanies times when the person experiences immobility. Reassuring the person that even a prolonged state of immobility will not last forever is likely to reduce levels of anxiety.

**Hallucinations:**

Hallucinations are usually due to the side effect of medications. They occur during wakefulness and are usually visual.

Auditory (hearing), olfactory (smell) and tactile (touch) hallucinations are rare in people with Parkinson’s disease. Tactile hallucinations can usually be traced to problems of the part of the nervous system. The other forms of hallucinations are usually due to medications.

**Thinking/cognition:**

A small portion of people with Parkinson’s disease usually many years after the initial diagnosis will experience problems with cognition.

**Difficulties learning and remembering:**

Some people may have slowness in recalling memories from a long time ago and also from a short time ago. When memory is reduced, the ability to learn new information is decreased. Being able to use a new skill from one day to the next can also be inhibited.
The reliance on prompts such as diaries and lists can decrease the impact of these problems.

**Sequencing:**

Sequencing tasks (ie doing tasks in a set order) such as when cooking a meal or assembling furniture may become harder over time. This reduction in ability may be due to a small loss in mental function, rendering the person slower at the task or more likely to follow written instructions rather than being able to do the task without any instructions.

**Information Overload:**

The person with Parkinson’s disease may feel “overloaded” after talking to someone for a long time.

If too much information is presented at any one time overload can occur. Considering many factors simultaneously, such as when making decisions can place stress on the person or make them feel overloaded. This does not help them to make clear decisions.

**Treatment:**

Treatment of Parkinson’s disease is symptomatic. Medication is used for the treatment of movement disorders. There are a number of prescribed medications that can be used for the treatment of Parkinson’s disease.

There are a number of potential side effects to using Parkinson’s medications. The person may experience any of the following: Blurred vision, difficulty sleeping, dizziness, upset stomach, decreased memory, decreased attention, headache, weakness, nervousness, sweating, fatigue and change in the ability to taste.

**References:**

The information provided has been adapted from the following sources:

Neurological Resource Centre (1998)
*Neurological Conditions Information Manual.*
Neurological Resource Centre of SA Inc
Unley, South Australia.

British Colombia Medical Association (2001)
Available online: [http://www.bcma.org](http://www.bcma.org)

National Institute of Mental Health (2002)
*Depression and Parkinson’s Disease*
Available online: [www.nimh.gov/publicat/depparkinson.cfm](http://www.nimh.gov/publicat/depparkinson.cfm)
National Parkinson Foundation (2002)
*Hallucinations*
Available online: www.parkinson.org

National Parkinson Foundation (2002)
*Problems “seeing” in People with Parkinson Disease*
Available online: www.parkinson.org

National Parkinson Foundation (2002)
*Sleep Disturbance in Parkinson’s Disease*
Available online: www.parkinson.org

*Parkinson’s Disease a Team Approach*
Southern Health Care Network
Cheltenham, Victoria.

*Moving Ahead With Parkinson’s*
Buscombe Vicprint Limited
Blackburn, Victoria.

**Support Group Contacts:**

In ACT:
Parkinson’s Society ACT Inc
Hodgson Crescent
Pearce.
Ph: (02) 62901984

In NSW.
The following contacts and their numbers have been provided by Parkinson’s NSW Inc:

Parkinson’s NSW Ph: (02) 97677881
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Bateau Bay Ph: (02) 43323153
Campbelltown Ph: (02) 46264959
Canterbury District Ph: (02) 97870000
Central Coast Ph: (02) 49732775
Coffs Harbour Ph: (02) 66492010
Deniliquin Ph: (02) 58813295
Dubbo Ph: (02) 68827778
Dundas-Parramatta Ph: (02) 98735180
Eastern Suburbs Ph: (02) 93690250
Eurobodalla Ph: (02) 44713261
Finley Ph: (03) 58831133
Foster/Tuncurry  Ph: (02) 65554992
Glebe Leichhardt  Ph: (02) 85855054
Glen Innes  Ph: (02) 67321252
Grafton  Ph: (02) 66422156
Hawkesbury District  Ph: (02) 45751403
Hornsby/Kuring Gai  Ph: (02) 94502238
Illawarra North  Ph: (02) 42846794
Illawarra South  Ph: (02) 42571945
Inverell  Ph: (02) 67210818
Junee/Cootamundra  Ph: (02) 69431515
Lockhart-Urana Naranderra  Ph: (02) 69205580
Lower North Shore  Ph: (02) 94115803
Newcastle  Ph: (02) 49540338
Orange  Ph: (02) 63629727
Parkes  Ph: (02) 68621259
Pittwater/Mona Vale  Ph: (02) 99971542
Port Macquarie  Ph: (02) 65840212
Shoalhaven  Ph: (02) 44239701
Southern Highlands  Ph: (02) 48864472
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Tweed Heads  Ph: (07) 55243872
<table>
<thead>
<tr>
<th><strong>Issue: Difficulties with walking</strong></th>
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</thead>
</table>
| **Implication:**  
People with Parkinson’s may be less confident in spaces that:  
- Are cluttered.  
- Have a lot of people.  

They may have difficulty doing more than one thing at a time. |
| **Solution:**  
Ensure that the space in the church and hall are free from clutter. Make sure the furniture is arranged to allow wide aisles or circulation spaces.  

Make sure door ways are not restricted by objects, as getting through narrow door spaces can be difficult.  

If children are present, remind them not to run indoors, or across the person with Parkinson’s. It is difficult for a person with Parkinson’s to have to watch out for the children, to judge their speed and to avoid bumping into them.  

If there are other things to attend to in the environment walking becomes more difficult.  

At morning tea offer to take the teacup to the table for the person.  

When moving around the environment, stop to allow them to look at things such as plants/wall hangings.  

Try not to talk to the person whilst they are walking.  

In the outdoor environment, make sure the paths are even and have enough space to allow for turning.  

Cut back plants to make sure they do not reduce the path width.  

Cut back trees, so they do not encroach on the space over the path.  

Make sure the path is well lit.  

Place handrails on both sides of steps to allow for some external support to provide stability.  

Provide rails in the toilet cubicles.  

Do not use the bathroom/toilet area as a storage space. |
### Issue: The person with Parkinson’s has a tremour.

**Implication:**
It may be more difficult for the person to pick up small objects. The person may tremour whilst sitting down, for example during the church service.

**Solution:**
If communion is provided in small cups at the pews, offer to pick the cup up from the tray for the person, as these trays are often cluttered with small glasses.

Provide a ledge for the person to place the hymn book or bible at the front of the pew.

Allow the person to chose where they sit, as they may feel self-conscious about their tremour.

The person may chose to bring something with which they can do purposeful movements to reduce their tremour. Allow them to do this when they feel the need.

### Issue: Reading can be difficult.

**Implication:**
Following the handouts, worship sheets, hymn books and Bible may be difficult.

**Solution:**
Use Large Print guidelines.

Ensure that the colour contrast is clear (ie. black and white rather than black on grey shading.)

Use sans serif font, (ie print with no feet, such as Arial or Verdana.)

Allow a wide margin, so that the person can follow the script using other forms of cueing, such as a ruler at the edge of the margin.

Provide plenty of space between the lines of the script.
### Issue: The person may experience periods of day time sleepiness, or periods of tiredness.

<table>
<thead>
<tr>
<th>Implication:</th>
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<tbody>
<tr>
<td>The person may find it difficult to participate in activities due to fatigue.</td>
<td>Chose to do activities at the time of day that best suits the person’s energy levels.</td>
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<td></td>
<td>Chose activities that can be broken down into smaller tasks, this way the person can do the activity until they are tired and resume the activity when they are feeling less tired.</td>
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<tr>
<td></td>
<td>Activities that can be broken down also allow for someone else to do parts of the activity that are difficult or that the person does not want to do. This allows the person to do the part of the activity that they can participate in easily.</td>
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<tr>
<td></td>
<td>If the person has had broken sleep, it is possible that the person’s carer may also have had broken sleep. Allowing the carer to have some respite may also help them to feel less tired.</td>
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</tbody>
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### Issue: The person may experience depression and symptoms associated with depression, such as: anxiety, loss of interest in activities, restlessness.

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<tr>
<td>The person may not join activities that they previously enjoyed before they became depressed.</td>
<td>If the person is anxious, try to find out the source of the anxiety and provide the relevant assurance.</td>
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<td>The person may be more difficult to engage in activities.</td>
<td>Sometimes anxiety is associated with a period of limited mobility or “freezing”, assure the person that this will not last forever, and acknowledge that it is difficult for them.</td>
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<td></td>
<td>Invite the person to participate in activities they enjoy. If they chose not to participate, respect the choice, and invite them the next time the activity or other activities are being held.</td>
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<td></td>
<td>If they are restless, try to provide and activity they can do. If they are not having too many problems with mobility, taking them for a walk in an environment that is pleasant and easy for them to negotiate may be helpful.</td>
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</table>
**Issue:** People may have difficulties with recalling information, sequencing tasks, or they may become overloaded with information.

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<td>Performing complex tasks, being in large groups, or having to make decisions out of a large choice range may be difficult or overwhelming for the person.</td>
<td>To aid memory recall and sequencing write lists, use a diary, or use visual prompts, such as photographs.</td>
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<td></td>
<td>Try not to present information that is superfluous to the subject or decision-making process.</td>
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<td>Don't present too many directions at the same time.</td>
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<td>Do activities in groups that are not too large, as too many people and too many “cross-conversations” may be overwhelming.</td>
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<td>If you are running groups, make sure there are adequate breaks, to enable the person to have a rest before fatigue or feeling overwhelmed occurs.</td>
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<td>Provide a quiet space where the person can go at any time, should they feel the need for a break.</td>
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