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# nursing care

of the person with **parkinson's disease**



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It is the hope of Parkinson's Queensland that the information contained in this booklet is found to be relevant and useful.

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For Parkinson's Australia



## introduction

This contribution to Parkinson's Queensland Inc attempts to fulfil the need to have available an information booklet which provides a practical guide to the nursing care of the person with Parkinson's Disease for nurses and interested allied health practitioners.

Parkinson's Disease (PD) is a degenerative neurological movement disorder affecting the dopaminergic pathways of the substantia nigra within the basal ganglia. It is generally a slowly progressive disease that manifests as interruptions to smooth coordinated movement but also has an impact on autonomic control (blood pressure, bowel and bladder) and mood. PD cannot be cured and treatment is aimed at symptom control. The primary rationale for treatment is either replacement of lost dopamine using the precursor levodopa or stimulation of the dopaminergic system using dopamine agonists. Parkinson's Disease is not a movement disorder confined to the elderly. Young onset PD also occurs following the same progressive path as PD diagnosed in the 7th or 8th decade. Diagnosis of PD occurs more commonly between the ages of 65 and 70 years. However, 10% of people diagnosed are under the age of 40 years. Thus it was considered that a baseline information guide on nursing care of the person with Parkinson's Disease should cover a broad age span.



## contents

### Contents

Clinical Symptoms	7
Cause	9
Onset/Early Signs	11
PD: The Nursing Care Challenge	13
Nursing Care Practice: Nursing Practice Interventions	15
• Initial Assessment	15
• Health Perception – Health Management	16
• Nutrition	17
• Swallowing and Speech	18
• Medications and Pain Management	19
• Elimination	22
• Activity-Exercise for Motor Dysfunction	24
• Sleep-Rest Pattern	25
• Dementia and Cognition	26
• Depression	27
Conclusion	28
Appendix 1	
Home Discharge Planning and a Note on Residential Care	30
Appendix 2	
Background – James Parkinson	31
Appendix 3	
Causes of Parkinson's Disease	31
Appendix 4	
Nursing and Medical Literature resources	33
References	34



**clinical** symptoms

#### Clinical symptoms consist of

- slowness of movement – bradykinesia
- absence of movement – akinesia
- rigidity or stiffness of muscles
- tremor – more commonly seen in hands, arms and legs but can also involve the jaw, face and head. The tremor and dystonic symptoms are initially unilateral then can progress to becoming bilateral
- postural instability or impaired balance occurs as part of the progressive nature of PD
- depression and anxiety are common

#### Other symptoms

- expressionless or masked face – hypomimia
- small, illegible handwriting – micrographia
- pooling of saliva resulting in drooling – due to impaired swallow reflex rather than excessive saliva production
- speech articulation and fluency are affected
- bed mobility dysfunction – turning over as well as transferring in and out
- constipation
- bladder disturbance



cause

Dopamine is a neurotransmitter with many functions within the nervous system. Dopamine is produced by neurones within the substantia nigra and plays a critical role in the control of coordinated, automatic movement. In PD, the dopamine producing cells within the substantia nigra become damaged or die off. The degeneration and cell death causes a reduction in dopamine levels and leads to interference of normal function of the basal ganglia. Researchers are attempting to understand why cell death or dysfunction occurs. Research continues to focus on environmental and genetic factors that may be involved. Many new treatments are aiming at neuroprotection in an attempt to slow the progression of PD.



The onset of PD is slow and may go unnoticed for several years. Symptoms of PD often present subtly. Many people initially blame symptoms on “ageing or old age”, muscle fatigue or overuse and do not seek a medical opinion until the symptoms interfere significantly with everyday activities or employment. The average age of onset is 65 years, with 10% being diagnosed before the age of 40.

#### Early Signs

- lack of hand dexterity
- shoulder stiffness (often misdiagnosed as “frozen shoulder”)
- joint and muscle pain
- development of a tremor confined to one side of the body
- dragging foot or stumbling when walking
- reduced arm swing (often commented on by others)

Any of the above signs can lead to a diagnosis of PD. However, a referral letter and subsequent clinical assessment by a neurologist with an interest or experience in Movement Disorders is often more likely to detect PD early.



## PD: the nursing care challenge

Nursing care of the person with PD presents unique and specialised challenges. Every person with a diagnosis of PD will present with an individual pattern of symptoms and different treatment priorities. What is troubling and disabling for one person will not be a problem for another. There may also be co-morbidities contributing to the person's overall level of health and wellbeing.

It is imperative that nurses caring for people with PD focus on:

- promoting the optimum health state possible
- provision of holistic care
- ensuring that medications are always administered on time
- prevention of illness
- maintenance of an acceptable level of health despite chronic disease
- safe yet enjoyable environment.

Nurses should acknowledge that in all interactions with a person affected by chronic illness such as PD that there must be:

- no intention of harm
- recognition of social background and cultural health beliefs
- respect for dignity

Consistency of care delivery is imperative. Precise communication and effective care planning should occur between nursing teams. Clear and concise documentation on care plans should include interventions that provide symptom relief for the person with PD. It is important to be aware of these interventions as they will assist in care delivery offered by nurses, regardless of experience with PD symptoms. Interventions should be simple and practical enough that they can be taught to carers, families and other health care professionals involved in the care of the person with PD.



nursing care practice

Nursing care practice will be defined by areas of care with suggestions for therapeutic interventions.

Nursing practice interventions:

- Initial assessment
- Health perception – health management
- Nutrition, swallowing and speech
- Medication and pain management
- Elimination
- Activity-exercise for motor dysfunction
- Sleep-rest pattern
- Dementia and cognition
- Depression

#### Initial Assessment of the Person with PD

##### Questions to Consider

- What level of communication skills does the person with PD have? i.e. Voice projection problems? Reduced facial expression?
- How cognisant is the person of PD? i.e. How are their day-to-day activities affected by the symptoms of PD?
- What is the level of discomfort and/or pain that he/she may be experiencing?
- Is there a willingness to form partnerships between the nurse and the person with PD in planning optimum care?
- Does the person possess sufficient knowledge and self-understanding regarding the effect PD has on them individually?

Nurses must have an awareness of these types of questions for direction of the care planning process.

There are interventions that will be more effective in some PD sufferers than others, dependent on the degree of dysfunction present.

## Health Perception – Health Management

### Assessment Guide Questions

- Does the person with PD understand and follow a prescribed treatment regimen?
- Are there problems with the regimen such as side effects, administration difficulties or difficult timetabling that causes resistance to follow medical instructions regarding medication dose and time?
- Is there a potential for injury?
- Is there a denial of illness?
- Is there a significant knowledge deficit?
- Is there any alteration in thought processes?
- What is the impact of impaired physical mobility?

### Intervention – Prescribed Strategies

- Listen to what the concerns are of the person with PD
- Open empathetic communication pathways
- Build a trusting relationship based on good rapport and sound knowledge of the disease process
- Assess for grieving over an altered body image
- Assess for a diminishing quality of life
- Ensure the person with PD has an adequate knowledge base regarding their medications
- Offer correct and sound advice about the time, dose and actions of PD medications.

If the nurse's own knowledge is lacking ensure inservice attendance or seek advice from health care professionals with experience in the treatment of PD. Alternatively, contact Parkinson's Queensland for additional literature.

## Nutrition

Eating the right food is important for any person, but for people with PD it is essential to maintain the right dietary intake. Difficulty with swallowing and chewing, or manipulating a knife and fork are frequent problems experienced by people with PD.

### Problems specific to PD

Research shows that food has an important role to play in the unpredictability of motor function. Two important findings related to food, PD medication and motor function ability are:

1. Different food causes the stomach to empty at different rates. This means the time taken for levodopa, a drug that converts to dopamine, to get from the stomach to the intestine (where it is absorbed) will vary.
2. Effect of the medication on symptoms may not correspond to the amount of levodopa in the blood stream. This is because of the competitive effect of amino acids which are also in the bloodstream. If a meal high in protein is eaten at the same time as the medication is taken, less levodopa will be absorbed into the intestine making less available to cross the blood/brain barrier.

Commonly used levodopa containing drugs in Australia – Madopar®, Sinemet®, Kinson®. Available in slow release/standard/rapid release formulas.

Other drugs used to treat Parkinson's are dopamine agonists. Dopamine agonists mimic the effect of dopamine at the receptor site. Commonly used agonists include Cabaser® and Permax®.

### Causes of Weight Loss in PD:

- tremor and dysknetic (involuntary) movement may use extra calories
- desire for food may be less because of reduced sense of smell, depression and possible cognitive impairment
- PD symptoms as well as medication side effects affecting movement of the hands and arms can slow down speed of eating making the person give up on the meal before it is finished
- chewing and swallowing dysfunction makes meal times difficult.

## Intervention

- It is certainly important the person with PD have a dietary review. A dietician with experience and knowledge of PD and related treatments is beneficial. Ensure that the dietician has understanding of the body's protein requirements and their competitive effect on levodopa levels. This often impacts on what the person with PD obviously needs from a nutritional point of view versus levodopa requirements.
- Dysphagia can often be improved by administering medication such as levodopa approximately 1 hour before food to minimise symptoms.
- Check denture fitting as well as oral mucosa for dryness, painful ulcers or tooth decay. The consistency and type of foods and fluids may need altering for safety and ease of eating.

## Swallowing and Speech

A speech pathology review can also be advantageous even for early stage PD. The aim is to detect and diagnose impaired swallowing as well as speech problems and recommend safe swallow techniques and eating positioning.

The recommended guideline interventions can assist nurses with care activities and people with PD to get and maintain the nutrition required.

### Food Types and Effect

**High protein foods** Necessary to assist with muscle repair and energy requirements. Helpful to space protein intake away from levodopa medication.

**Low protein foods** Will have faster gastric emptying time.

**High fat foods** Delay gastric emptying.

**High sugar foods** Good source of energy if excessive tremor or dyskinesia is present. Ensure good mouth hygiene as tooth decay and mouth infections can be exacerbated by high sugar content.

**Temperature of food and fluid** Gastric emptying is delayed by chilled fluids (4°C) and hot fluids (50°C). Body temperature (37°C) has fastest emptying time.

## Fibre

Fibre has an important role in digestive health and bowel habits. Care must be taken if the person with PD has suspected autonomic dysfunction as intestinal motility may be compromised. Large intakes of high fibre foods may be detrimental in people with PD who have long standing chronic constipation. It is important to consult expert medical opinion so an informed approach to adding fibre to the diet is taken.

## Outcomes

- Maintain good fluid intake
- Control constipation
- Manage and treat problems such as dry mouth and dysphagia
- Time medications in relation to food to ensure best levodopa action possible
- Manipulate protein and carbohydrate to achieve predictable medication responses.

## Medications and Pain Management

Medications used to control the symptoms of PD are the most common form of treatment available. The main groups are:

- dopamine replacement in the form of levodopa
- dopamine agonists to stimulate the dopaminergic system as well as theoretically provide a degree of neuroprotection.

There are several other classes of medications used to enhance the action of levodopa or assist with treatment side effects. Parkinson's Queensland has information regarding the available pharmaceutical treatments currently used in Australia – this information is readily available.

Anecdotally, many people with PD can relate an experience such as this:

*"When my medication is working, I can almost be a normal human being.*

*At first my medications took care of me completely. Those days are gone. I am not all right all day anymore. It's a little frustrating..."*

This is an experience describing motor fluctuations, known as the “on/off” phenomenon. This can occur after 2-5 years of levodopa use to control PD symptoms. Frequently people with PD can predict a response from usual medications that provides symptom relief and improved motor ability. Often as the levodopa dose has peaked and blood levels begin to decline, the clinical features of PD will worsen causing severe disability and dependence on others for care needs. However, unpredictability of medication response can occur with some medication doses providing limited or no symptom control. Reasons for this are poorly understood.

Not only do peaks and troughs of medication levels occur but psychological factors can have a significant impact on the effectiveness of treatment. Non-motor symptoms of PD are also common such as anxiety, muscular cramps (common in the foot and great toe), sleep disturbance and autonomic dysfunction.

### Intervention

#### Medications on Time

This would be the **most important nursing activity** performed for an inpatient with PD. When medications are effective, and a strict timetable of administration is adhered to, the patient will have the ability to perform most of their own cares. If doses of levodopa are missed or late this can have a profound impact. Physical ability, mood and anxiety levels often take days to return to an acceptable level of symptom control.

- Assess the patient for their ability to self-administer if this is appropriate.
- Encourage the use of pill timers and cues to remember when medication is due.

The patient who has a poor understanding about how their PD medications work will be more likely to miss doses because they are feeling well resulting in disabling “off” periods that are difficult to control.

#### Concomitant Medications – Pain Relief

Origins of discomfort and pain are often musculo-skeletal in PD. If arthritis or osteoporosis are also present pain is often difficult to control. Doctors may prescribe simple analgesics such as paracetamol initially, then an addition of codeine which can be useful for dystonic cramps. Anti-inflammatory medications remain first line treatment for arthritis conditions. Be aware of the impact of over the counter medications on body systems and prescribed medications – seek advice as required.

Medical staff need to be made aware of concerns regarding:

- pain control
- anxiety
- confusion

while on prescribed medications.

#### Other Medications

It is important to check the interactions of many commonly used medications:

Metoclopramide (e.g. Maxolon®) or prochlorperazine (e.g. Stemetil®) are frequently given for nausea and vomiting and Haloperidol (Serenace®) for acute confusion – these have a major impact on PD by worsening symptoms. Alternatives are available and should be used in preference to these drugs. The cause of any acute confusion should be thoroughly investigated – PD is not an acute disorder.

Many other medications can be added to the PD treatment regimen, polypharmacy is common in the treatment of PD. These will usually be added to reduce the side effects of dopaminergic drugs so mobility and function can be maintained. Often even experienced physicians, nurses and pharmacists may be unclear about the combination of medications prescribed for people with PD. If there is any lack of clarity about drug orders, ensure they are questioned and answered. Do not just withhold medications – they may have a very important role in the overall control of PD symptoms.

## Elimination

### Bladder Problems

**Frequency** Urgency occurs due to the effect of PD on the detrusor muscle of the bladder. The muscle will spasm and become dystonic similarly to skeletal muscles. This causes a feeling of urgency and often the bladder will empty. Frequency at night time is also common- this may be related to alteration in blood pressure when lying down (as in attempting to sleep). Blood pressure returns to normotensive level resulting in increased renal perfusion causing increased urine production and a full bladder results in nocturia. During the day the nature of PD medications often produces hypotension which results in lower renal perfusion and lower levels of urine production.

**Infection** Compromised swallow and excessive tremor or dyskinesias all result in inadequate fluid intake or increased fluid requirements. Urinary tract infections are not uncommon and any alteration in mental state in PD must be thoroughly checked out including the presence of infections. Care must be taken with the use of macrolide antibiotics and their interaction with current PBS available dopamine agonists.

Many medications used in the treatment of PD can alter the colour and odour of urine. The COMT inhibitors (Comtan<sup>®</sup>, Stalevo<sup>®</sup> which contains Comtan) commonly turn urine an orange colour. It is not uncommon for levodopa preparations to change the colour and odour of urine also.

### Intervention

It is important for any symptoms of dysfunction to be checked by a urologist as the risk of enlarged prostates or other renal conditions still have to be excluded or treated if they exist.

Avoiding UTIs may not always be possible but a sensible fluid intake should be encouraged being mindful of any heart condition which may require monitoring

of fluid levels. For the inpatient with PD a fluid balance chart and food chart can be assistive. Encourage adequate fluid intake, monitor output and check out any possible UTI.

Bowel Problems:

- Constipation
- Diarrhoea
- Autonomic Dysfunction.

### Intervention

#### Constipation

Bowel regularity is difficult at times to maintain and is common in PD.

Constipation can be treated with a sensible fibre diet, fresh fruit, vegetables and fluids. A morning glass of pear juice (250ml) has been very effective for many people with PD. It is important to keep the faeces soft. Aperients, suppositories, microlax enemas, oral iso-osmotic agents may be necessary when constipation becomes problematic. Faecal incontinence can indicate severe constipation which requires medical referral, review and treatment.

Diarrhoea can be related to medications, diet changes or, as mentioned, faecal impaction. If diarrhoea is prolonged this must be reviewed medically to exclude infection or bowel dysfunction. Treatment must be initiated to prevent electrolyte imbalance and malabsorption.

#### Autonomic Dysfunction

Autonomic dysfunction can occur in PD. This can present as slowed peristaltic action of the bowel resulting in altered absorption of food, delayed gastric emptying and unreliable medication effects. On x-ray examination the bowel can often appear enlarged (megacolon) with faecal impaction not uncommon. This requires a gastrointestinal specialist review and re-evaluation of the diet. A bland, low fibre diet is often initiated.

## Activity Exercise for Motor Dysfunction

### Main Symptoms of PD Movement Dysfunction

**Gait** A “shuffling” gait is a common clinical observation of the person with PD. Reduced arm swing, slumped trunk and unilateral foot drag are also common signs.

**Freezing** This refers to the breakdown of repetitive, automatic movement such as walking, hand writing and even speech. The person with PD will become “stuck on the spot” and is often unable to start moving – described as gait ignition failure. Encouraging the person to think about stepping over an imaginary line is often a useful strategy. The person may also experience difficulty with ending movements.

**Dystonia/Dyskinesia** These are the most common abnormal movements noticed and observed in PD. Dystonia is often related to the “off” symptoms of PD. Stiffness, slowness, rigidity and “pill-rolling” tremor fall into this category.

Dyskinesias are often related to the “on” phenomenon experienced by people with PD. Dyskinesias present as more fluid, uncontrollable muscle activity and are often a side effect of levodopa treatment.

**Postural Instability** This tends to be a symptom of advancing PD. The practitioner needs to be especially aware of care giving practice where the PD person's poor balance is involved, e.g. mobilising for:

- walking
- transferring, particularly when getting out of bed at night.

There is very little pharmacological treatment for impaired balance and strategies taught by a physiotherapist and reinforced by nurses in their care planning may be the most effective treatment.

### Intervention

#### General Exercises

- Encourage safe gentle exercise that suits the individual – everyone's abilities, motivation and concurrent health problems will be different.

Contact Parkinson's Qld Inc for:

- self help information booklets and instruction sheets
- information on community physiotherapy groups
- local community Parkinson Support Groups may have a physiotherapist guest speaker or exercise information sessions
- information on university programmes which are frequently conducted to assist people with neurological disorders and their exercise requirements.

Nurses can provide assistance with:

- reinforcement of specific physiotherapy techniques
- gentle stretching
- create awareness of slowness of movement – provide cues such as rhythmic sound or visual guide for length of stride
- encourage straight posture and improved arm swing which is often overlooked by people with PD until they are reminded.

It is important when seeking physiotherapy assessment and intervention that the therapist has experience in treating PD, or that they have access to experienced therapists for advice. There are PD specific, research based techniques and strategies that can be very beneficial for symptom control. It is important that physiotherapy assessment and techniques are useful and appropriate.

### Sleep-Rest Pattern

“Off” periods that cause tremor, muscle stiffness and dystonic cramping can often make the person with PD very fatigued. Difficulty sleeping may be caused by limited bed mobility, nocturia or long periods of time without medication. Night-time cramps and restless legs can also impact on falling asleep and staying asleep.

Any severe daytime sleepiness can in some cases be attributed to medications used to treat PD, particularly dopamine agonists. However, it is important that conditions such as sleep apnoea and snoring are investigated and treated as this can have a profound effect on daytime fatigue.

### Intervention

- Wearing nightwear made of fabrics such as silk or satin can assist with bed mobility – turning and repositioning
- For restless legs – lying supine or on the side with a pillow beneath the knees or between the knees brings relief
- Discuss PD medications with medical specialist or GP as some slow release preparations may assist in overcoming nocturnal dystonic symptoms. Night sedation may also be appropriate and useful
- Encourage small rest times during the day if possible, 20-30 minutes, avoid oversleeping
- Encourage a good daytime and night-time routine
- Watch night time oral intake – for nocturia it is probably useful to reduce fluid intake after 4pm. Encourage avoidance of stimulating substances such as caffeine after this time
- Maintain a check on daytime postural blood pressure and notify medical staff of any significant hypotension – this could also be contributing to an increase in nocturia and can be investigated and possibly treated.

### Dementia and Cognition

A common question asked by people with PD and by family and friends is that of dementia and PD. Studies show that there is deterioration in intellectual function with PD. Other post-morbid brain studies dispute this. Alzheimer's Disease is dementia with Lewy bodies which have also been found in the brains of people with PD. These Lewy body inclusions are considered to be the possible cause of cognitive dysfunction such as memory decline and confusion. Lewy bodies are found in selected subcortical structures including the substantia nigra which is primarily affected in PD. However, the significance of diffuse Lewy body disease is under debate. The toxicity of metabolites of levodopa in the brain is also being researched for the role on cognitive decline in PD.

### Intervention

- Encourage activities that keep mind active and the person with PD interested.
- Ensure any behavioural changes are documented and communicated to the medical specialist as a confusional state could be a presentation of an underlying infective process or medication side effects

- Assist in allowing the person with PD to remain as independent as possible and encourage any activities that promote quality of life
- Listen to what the family and carers are saying about any personality changes.

In the minority of PD cases nursing care practices for dementia may need to be implemented.

### Depression

Depression and anxiety are common. In addition to motor fluctuations there also exists non-motor symptoms such as mood changes, depression and anxiety.

Another aspect nurses must consider is that despair, anxiety, anger and depression features in a person's behaviour when they are experiencing progressive decline in abilities to independently carry out daily living activities. Depression may also manifest as the person becomes increasingly dependent on family caregivers, medical specialists, other allied health professionals and nursing care.

While depressive disorders can coexist with dementia in PD, families and clinicians may also misinterpret impaired cognition as a sign of depression and seek antidepressant treatment. The distinction is important, since PD people with dementia are especially vulnerable to psychoactive medication effect. This could result in the development of delirium, a leading cause of nursing home placement.

### Intervention

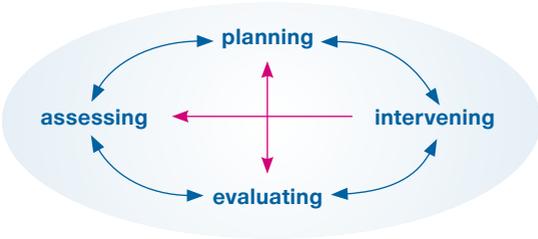
Assessment of cognitive impairment levels should include:

- executive dysfunction
- visual-spatial impairment
- memory impairment
- attention deficit.

Neuropsychologist's can perform assessments to distinguish depression from cognitive decline and an assessment referral may often be appropriate. Nurses may also seek inservice education for techniques to care for and understand the processes of cognitive decline so that best practice is being utilised.



To deliver sound nursing care for the person suffering from PD, an understanding of the signs and symptoms, causes and the various strategies which may be employed, is important so that interventions are consistently beneficial. The process which guided the nursing care suggestions here is illustrated in the familiar diagram below:



It is important to remember that while there are generic clinical features of PD every individual will have a variety of symptoms, their own experience, their own set of priorities and own level of self care. Each individual's perception of quality of life will be different. All interventions implemented to assist with daily activities should revolve around the priorities of the person with PD and ensure maintaining the best level of health possible.

**Never Give Up**

- Remain positive in the care of the person with a chronic and progressive condition. Focus on simple outcomes. As each is achieved this should create positive encouragement for the person with PD, carers and health care professionals involved in their care.
- Seek solutions to problems from health professionals with experience and expertise in PD treatment. Never give up hope, for others have dealt with similar problems and there are solutions with lateral thinking and team work.

## Appendix 1

### Home Discharge Planning and Note on Residential Care

#### Home Management

Management at home is desirable as long as possible.

People with any progressive, chronic illness are very reluctant to give up the security of their own home environment. Modifications to the house can reduce the burden on family carers and help the person with PD maintain independence, keep mobile and stay safe.

#### Intervention

- Occupational therapists can provide home assessments and observe for any areas around the home that are difficult to access or are a safety risk. These can often be provided as part of government funded services.
- Rails in the bathroom and by steps will improve safety
- Removal of rugs that can cause falls, as well as visual strips placed in areas of the home where freezing and gait problems occur is helpful. Physiotherapists can also provide in home assessments to assist with these problems.
- The role of the nurse for in home care is to assess safety issues, reinforce physiotherapy techniques, observe for family dynamic dysfunction (importantly – carer burden) and reinforce the medication regimen.

- It is important that any potential problems be communicated to the appropriate health care professional involved and referrals made as problems are discovered so that solutions can be found in a timely manner.

Community nurses and PD nurse specialists are in a unique position to co-ordinate and make appropriate referrals as required and provide continuous evaluation of any interventions put in place.

#### Notes on Residential Care

As self care deficits increase and carers are no longer able to provide the assistance the person with PD may require often residential care is required or recommended. This care occurs either as a permanent resident in an approved facility or respite care.

It is important for nurses to understand the improvements in physical condition an appropriate medication regime can bring about.

Providing strategies and maintaining a prescribed medication regimen can assist with minimising PD symptoms and allow the person to carry out their own self cares and mobilise independently.

Care planning and the level of care required must be carefully assessed and carried out with the person with PD, their family and other involved health professionals involved in the process.

The objective of any care plan should be to improve overall quality of life and independence, reduce discomfort and provide assistance during periods of severe PD symptoms.

## Appendix 2

### Background – James Parkinson 1775-1824

Considerable advances were made between the seventeenth and nineteenth centuries in neuropathology – researching the relationship between the brain and the nervous system. For example, it was shown in the 1650s that stroke was due to haemorrhage from cerebral vessels thus impacting on movement. By the nineteenth century particular clinical conditions were beginning to be traced to specific nerves. In 1811, Charles Bell demonstrated that damage to the seventh cranial nerve produced facial paralysis – Bell's palsy.

During the early 1800s clinicians had observed a neurological disorder commonly referred to as paralysis agitans but there had not been any attempt to group together its symptoms. Parkinson, in 1817, published An Essay on the Shaking Palsy – the first comprehensive description of the condition which bears his name. PD is now usually described as a progressive (degenerative) condition involving a disturbance in the neurological co-ordination of voluntary movement.

The pursuit of a better understanding of the brain and the nervous system continues and, despite outstanding achievements, neurology research shows that conditions remain intractable, especially with an ageing population (Porter, 1997).

## Appendix 3

### Causes of Parkinson's Disease

#### The most frequently asked question is – what causes Parkinson's Disease?

Dr George Mellick, Neuroscientist and Post Doctoral Research Fellow, University of Qld Dept of Medicine, Princess Alexandra Hospital, wrote a synopsis of current theories on the matter for PQL. As a way of responding to the question, in the context of extending nursing knowledge in the care of the person with PD, it is appropriate to quote Dr Mellick.

#### Biological Theory

Between the years 1918-1932 there were several worldwide epidemics of a brain virus resulting in a condition called encephalitis lethargica (sleeping sickness). A number of neurological symptoms occurred in people exposed to this viral infection, including the features of Parkinson's. This led some experts to suggest that all Parkinson's Disease was caused by a viral infection. With the disappearance of encephalitis lethargica from the world in the 1930s, some doctors even predicted that Parkinson's would disappear. Sadly, this did not occur and the biological theory for the cause has subsequently subsided.

### Environmental Theory

Epidemiological studies (which compare groups of people who suffer from Parkinson's to closely matched control groups who do not have Parkinson's) have shown that factors such as living in a rural setting, drinking well water and being exposed to pesticides, are more common in Parkinson's groups compared to control groups. This suggests that an environmental factor (perhaps an environmental toxin) may be associated with the cause of Parkinson's.

To date, despite extensive research, no naturally occurring chemical has been implicated in the development of Parkinson's.

### Genetic Theory

It is well known that around 20% of people with Parkinson's have a history of the disease in the family. This is about three times the chance of having a family member with Parkinson's in the remainder of the population. This has suggested that inheritance may play a role in the cause of Parkinson's, although it may just reflect the fact that most family members live in the same environment.

There are also well defined families worldwide which contain many family members (of several generations) who have Parkinson's. It is possible that in these families, Parkinson's may be caused by a "bad gene". The existence of such a genetic cause for Parkinson's has recently been discovered in a large Italian family known

as the Contursi kindred. In this family, those people with Parkinson's have a different form of the synuclein gene. We do not know yet what the function of the synuclein protein is or how the "bad gene" may lead to Parkinson's. However, we know that this is not the cause of Parkinson's in most people.

### Other Theories

There are other theories that have been suggested as contributing to Parkinson's. These include the idea that Parkinson's may be triggered due to the body not being able to adequately deal with damaging chemicals, called **free radicals**, which are regularly produced in the brain during chemical oxidation.

### A Combination of Theories

Many researchers today believe that most Parkinson's results from a **combination of genetic and environmental factors**. That is, there is something in our environment which we may all come into contact with that may cause Parkinson's only if we are genetically susceptible. This idea is similar to the idea that over exposure to the damaging rays of the sun can lead to skin cancer, but that some people (particularly those with fair hair and complexion) are at greater risk.

## Appendix 4

### Nursing and Medical Literature Resources

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