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Your Client has Parkinson's...

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# Minister's foreword

# Minister's foreword for "My Client has Parkinson's" brochure

The positive impact of education and awareness on the quality of care a person can provide cannot be underestimated. That is why I am very pleased to present this brochure, which aims to assist workers to better understand Parkinson's, one of the most common neurological disorders.

The information in this booklet can help workers who care for people who may have Parkinson's to appreciate this complex, disabling condition which affects an estimated 80,000 Australians. Interestingly, while the disease is most

commonly associated with older people, some 12,000 Australians of working age are living with Parkinson's.

Although there is a degree of general awareness about Parkinson's in the community, knowledge of the disease and the ability to identify it is not so prevalent, even in our professions.

This brochure aims to bridge that gap. It sets out clearly what Parkinson's is, what causes the disease, signs and symptoms, and importantly, what care considerations should be made.

I encourage all community care workers to pick up a copy of this practical resource and pass it on the others who may find it useful to increase the quality of care experienced by people with Parkinson's.

John Ajaka

Minister for Ageing

Minister for Disability Services

Minister for the Illawarra



Freezing Commonly known as freezing of gait (FOG) where the feet

become stuck to the ground and the person is unable to move forward again for several seconds or minutes. This is common whilst starting to walk, turning, walking through doorways, walking over different floor surfaces or walking through narrow corridors. Freezing can also occur to

upper limbs, speech and eye lids

**Hallucination** Seeing objects or hearing voices that do not exist

**Hypomimia** Decreased facial expression caused by rigid facial muscles,

also called masking. It can occur around the eyes resulting

in reduced blinking and staring

Micrographia Small tense handwriting, which can become illegible

**Motor fluctuation** Motor control movements that can vary in severity,

frequency and duration

On/Off phenomenon Unpredictable loss of function and movement that may be

related to the 'wearing off' of medication. In an 'OFF' state, the person may experience stiffness and slowness and may not be able to move or perform their usual daily activities. This 'OFF' state can be predictable in some people when they know that the effect of their medication is 'wearing-off' and therefore they will be able to plan activities around their 'ON' times when their medication is working at its best

Pill rolling movements Where the thumb rhy

Where the thumb rhythmically moves along the first

two fingers

Resting Tremor Shaking of relaxed limbs which decreases during active

movement. It can also increase or be exacerbated if the

person becomes anxious, stressed or excited

Rigidity Abnormal stiffness of muscles, commonly of the neck

and upper and lower limbs

Sialorrhea Abnormally high salivation (drooling)

<sup>\*</sup> This Glossary includes terms that do not appear in this booklet. They are however commonly used in reference to Parkinson's.

# **Glossary of terms\***

My client has Parkinson's

Akinesia Inability to move

Ataxia Loss of balance

Autonomic nervous system Responsible for controlling body functions such as heart rate, blood

pressure, bladder and bowel or intestinal function and the ability

to regulate body temperature

Basal ganglia A group of nerve cells in the brain responsible for the coordination

of automatic movements

Blood-brain barrier A membrane in the brain that separates the blood stream from

the brain tissue

Bradykinesia Involuntary slowing of movement

Bradyphrenia Slow thinking and other mental processes

**Cogwheeling** Rigidity of a limb which, if moved, gives way in a series of small

stages, similar to the steps of a cogwheel

**Depression** A state of low mood and aversion to activity that can have a

negative effect on thoughts, behaviour, feelings and physical

well-being

**Dopamine** A neurotransmitter in the central nervous system that assists with

transmitting signals between the substantia nigra and the corpus

striatum to produce smooth, purposeful muscle activity

**Dysarthria** Low voice that is often muffled

**Dyskinesia** Abnormal involuntary body movements that are a common side

effect of long- term levodopa treatment, resulting in repetitive jerking or twisting movements of either the torso, limbs or the

neck and face (the lack of co-ordination)

**Dysphagia** Difficulty in swallowing

Dysphonia Difficulty speaking, resulting in a low flat monotonous speech

or hoarseness

Dystonia Spasm-like, abnormal muscle contraction resulting in abnormal

movements and postures which can be painful

**Festination** Walking with small quick steps as if trying to keep balance

This learning package has been developed to assist workers in the Australian Government Home and Community Care Program (HACC) and the NSW Government Community Care Supports Program understand the impact of Parkinson's on people living with the condition, their families and carers. It also aims to provide advice on how to interact, care and provide support to people living with Parkinson's.

For educational resources, general information, healthcare professional referrals and support networks, please call the Parkinson's NSW Information Line on 1800 644 189, visit the website at www.parkinsonsnsw.org.au or email pnsw@parkinsonsnsw.org.au.

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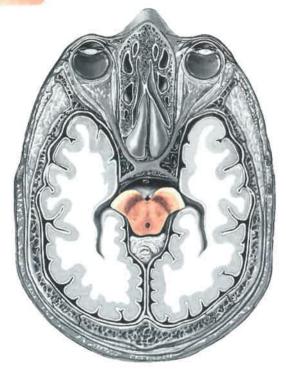
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Parkinson's



# **Summary**

We hope you have found the information contained in this booklet useful. Below is a summary of the key points:

- Remember how the condition affects the person and that symptoms can vary from day to day and hour to hour
- Taking medication at the exact due time is crucial for people with Parkinson's. Make sure they take a dose with them when they go to doctors' appointments, other appointments or even shopping. You never know what may delay their return home
- Listen to the family and the person who has Parkinson's they are the experts
- When communicating with the person with Parkinson's give them the time to respond to any questions or instructions
- Be patient. Do not rush the person with Parkinson's and give them time to perform daily activities
- If you are going to be late try and call the person you are visiting to let them know
- Report any changes or concerns to your manager as soon as possible

Contact Parkinson's NSW for further informations and fact sheet.

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# What is Parkinson's?

Parkinson's is a chronic, progressive, complex condition. It is one of the most common neurological disorders in Australia with an estimated 80,000 people living with the disease.

There is a misconception that Parkinson's only affects the elderly, however, it can occur at any age, with 10% under the age of 40. The disease will have a varying impact on each person, some will have a fast progression, while for others the progress is slower.

Therefore your clients ages are going to vary. Some will have had the disease for many years (maybe as long as fifteen years), while others requiring assistance may have been diagnosed in recent years, (three to five years). Symptoms of the disease varies from individual to individual. What you see in one person you may or may not see in another.

Other factors may affect the person with Parkinson's (PWP), this includes other illnesses e.g. infections, diabetes, hypotension, heart diseases etc., as well as the age of the person and progression of their condition.

# What is Parkinson's?

# Parkinson's is a disorder of the brain (neurological) resulting from the degeneration of nerve cells in an area of the brain called the substantia nigra.

The nerve cells in the substantia nigra produce a chemical called dopamine which acts as an electrical impulse (communicator) to other areas of the brain to allow smooth and coordinated functioning of the body's muscles and movement.

These alterations in movement is what leads to the diagnosis of Parkinson's, and why so many people incorrectly thought that Parkinson's was just a movement disorder. It is so much more.

Before any physical symptoms are observed as a result of Parkinson's, a person may have lost up to 70% of their dopamine producing cells.

The loss of dopamine means that a chemical imbalance has occurred in the brain. This imbalance affects other chemicals in the brain including serotonin, which affects mood and emotions and may explain why many people with Parkinson's may show symptoms of depression and anxiety. Therefore Parkinson's is not just a movement disorder.

# **Care considerations**

# Getting into a car

The following is a general approach for a client that is mobile and has been assessed as requiring minimal assistance.

- Open the door to ensure that it will not close accidentally, holding if necessary
- Ask the person with Parkinson's to hold the frame of the car and the dashboard and sit down on the car seat
- Ask them to let go of the frame of the car and the dashboard and lift their feet into the car
- They should then be able to re-adjust themselves so that they are sitting comfortably in the car

If movement on the car seat is difficult, suggest using satin material, a drawsheet or plastic bag. If a plastic bag is used then remember to make sure that the person with Parkinson's is aware that it is for movement purposes only and not because you want to keep your car clean or you think they may have an accident, such as incontinence.

# Getting out of a car

This is the reverse of getting into a car.

- Ask the person with Parkinson's to shift forward, turn and put their feet on the ground
- Ask them to hold onto the car frame and dash board, lean forward and stand
- It is important to make sure they are stable on their feet









# What causes Parkinson's?

There are many factors involved in the explanation as to the cause and/or why people get Parkinson's. There are small numbers that are hereditary and also a number of genes have been identified that may put people at a higher risk.

Research plays a continuing role in determining the cause and/or susceptibility of Parkinson's.

Currently there is no known reason for the development of Parkinson's, however it is thought that a combination of the following may play a role:

Genetics (heredity)

Aging



# What are the signs & symptoms of Parkinson's?

The signs and symptoms that lead to a diagnosis of Parkinson's are called motor symptoms. Motor symptoms are visible symptoms, the ones that we see or the person can feel. The four Cardinal Symptoms are:

#### 1. Tremor

A resting tremor is present in approximately 70 percent of people diagnosed with Parkinson's. The tremor usually occurs when a person's muscles are relaxed and reduced or absent during an activity and may become worse when the person becomes anxious, stressed or excited. The tremor is commonly seen in the hands, arms, legs and can also be seen in the face or head.

There are two types of tremor

- External tremor, the one that we see (shaking); and
- Internal tremor, the one the person with Parkinson's feels.

### 2. Bradykinesia – Slow movements

Due to chemical changes in the brain movement becomes slower as messages struggle to get through. Older people may put this down to the ageing process, however in people with Parkinson's the slowing down may become more rapid. This can be the most disabling of all the symptoms and may affect many aspects of activities involved in daily living such as tying shoelaces, writing with a pen and using a knife and fork.

### 3. Rigidity - Stiffness

Rigidity refers to stiffness of muscles which seem unable to relax and are tight even at rest. This can be painful and lead to stiffness of joints. This is known as cogwheel rigidity (short, slightly jerky movements). Some problems that can be associated with rigidity are freezing, reduced facial expression, difficulty rolling in bed and getting in and out of a bed, chair or car.

### 4. Postural Instability

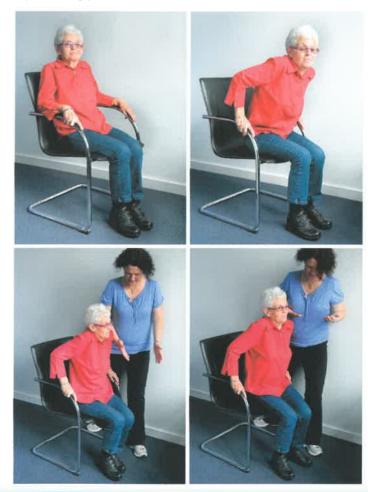
A person with Parkinson's may have problems with balance and may be at a high risk of falls. This normally occurs at a later stage in the progression of Parkinson's and can be caused by a number of factors. The person with Parkinson's may have slowed down and may have a wide based gait and/or

- Shuffling steps
- Stooped posture

## Getting out of a chair

- Ask the person with Parkinson's to move to the edge of the chair and lean forward
- They should then be able to push up from the arm rests (sometimes, they may need to rock back and forth to be able to then push themselves off the chair) and stand

If they have problems getting out of a chair, it may be useful to ask them to sit on satin material or a plastic bag placed on the seat of the chair to assist them in sliding forward.



## **Getting into bed**

- If they are able, ask the person with Parkinson's to pull their blankets back and sit near the pillows
- The person with Parkinson's should then be able to lift their feet onto the bed and lie down

## Getting out of bed

This is the reverse of the above.

- Ask the person with Parkinson's to push the blankets off their body and roll to the side of the bed. If they have a rail, ask them to hold on to the rail for support
- Ask the person with Parkinson's to push themselves into the sitting position and place their feet on the ground

Many people with Parkinson's find it useful to have satin inset sheets or satin pyjamas, which help the movement in and out of the bed by providing a slippery surface. Alternatively, plastic bags or plastic sheeting can be used and removed once the person is settled.

It may be useful to use 'cueing' techniques as discussed earlier. By allowing the person with Parkinson's to do as much as they can so helping them to maintain their independence. If you find that they require additional assistance or aids you will need to report back to your manager and their family or carer.



Motor	Sensory	Cognitive	Autonomic
Slowness	Numbness	Mood changes	Hot/Cold sensation  – difficulty in regulating body temperature
Tremor	Aching- joints or general aches	Depression or sadness	Bladder problems  - incontinence or retention of urine
Stiffness	Restlessness	Anxiety	Sweating
Postural instability	Pain	Panic attacks	Abdominal discomfort
Shuffling gait	Insomnia	Confusion	Constipation
Decreased arm swing(s) when walking	Disrupted sleep patterns	Slowed thinking	Sialorrhea – excessive saliva or drooling
Stooped posture	Excessive daytime sleepiness	Difficulty in doing more than one task at a time	Urinary frequency and/or urgency
Weakness		Hallucinations	Erectile dysfunction in men
Low voice volume		Behavioural changes such as impulse shopping, hypersexuality and gambling	Hypotension
Swallowing difficulty		Preoccupied with time or clock watching	Postural hypotension
Reduced dexterity		Dementia	
Freezing			
Masked face, reduced facial expression			
Micrographia (small handwriting)			
Crampe in the lage arms			

Cramps in the legs, arms or torso

# What treatments are available to people with Parkinson's?

There is no known cure for Parkinson's, but there are treatments that are effective in helping to relieve or minimise the symptoms.

Treatments for Parkinson's work in three ways:

- By replacing the level of dopamine in the brain
- By mimicking the actions of dopamine, and
- By extending the life of dopamine in the brain

People with Parkinson's may have different combinations of drug therapy which they need to take at different times. It is important for you to understand what medication they take so that you can make sure they don't miss a dose or take their medication late. If they are unable to take their drug at the right time, the balance of the chemicals in their body can be severely disrupted and their symptoms could return and severely disable them for hours.



### How can you help?

It is important to find out if the person with Parkinson's has any special dietary requirements and what foods they like to eat. Some people with Parkinson's may not be aware that they have a problem with swallowing and you may be the person to identify this. One of the first indications that a person has a problem is coughing after drinking a glass of water.

If this happens more than once you should report your concerns to the family, carer and to your manager. The following are some points to consider:

- Allow the person with Parkinson's to concentrate on eating.
   Do not encourage talking at the same time
- Allow for time to eat. Sometimes it may be necessary to reheat the meal
- Ensure the person with Parkinson's is sitting in an upright position and is comfortable
- Reassure them if they become embarrassed because they are taking too long to eat or have food spillages



## Swallowing problems

Many people with Parkinson's will have some problems with swallowing.

This can lead to the following conditions:

#### Malnutrition

Not eating enough food to maintain good health leading to illness or risk of infection

#### Aspirate pneumonia

An infection in the lungs as a result of food, liquid or secretions going into the lungs

#### Dehydration

Not having enough water to drink causing such problems as constipation and bladder infections

#### Choking

Food getting stuck in the airway and leading to breathing difficulties

#### Weight loss

Not having balanced meals, including protein, carbohydrates, vegetables and fruit, resulting in weight loss and fatigue

People with Parkinson's are advised to seek assistance and assessment from a speech pathologist who will:

- Assess their swallowing ability
- Give them exercises to maintain their swallowing reflex
- Assist in maintaining voice production
- Provide advice on the most suitable foods to eat from a normal diet to soft or thickened fluids depending on their assessment and the progress of their disease.

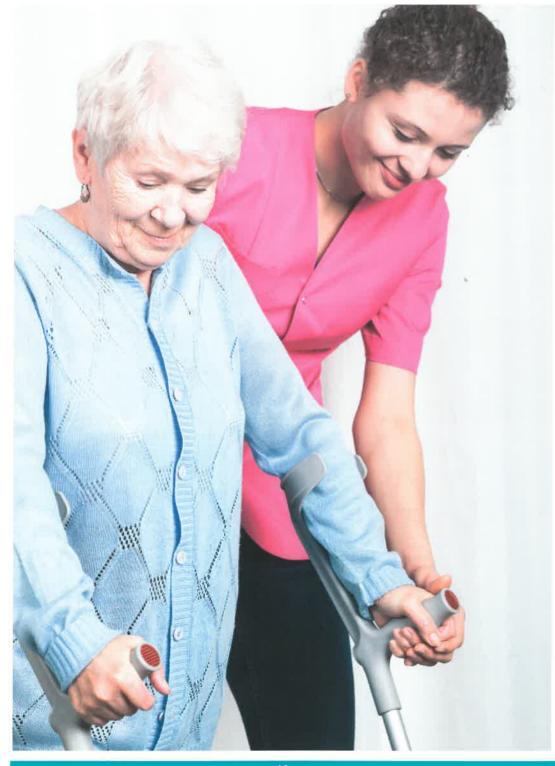
Most people with Parkinson's will have some kind of prompt to remind them when they need to take their medication. If they do not have a prompt, it may be helpful to suggest that a pill timer or an alarm system may assist them.

To avoid any late or missed doses it is advisable that people with Parkinson's take their medication with them wherever they go, whether it is a doctor's appointment, appointment running late, cars breakdown, have flat tyres or simply out shopping. This will ensure that they are never 'OFF' when they are out.

### What is meant by 'ON' and 'OFF'?

When a person is 'ON' their medications are effective, they are able to function at an optimal level.

When a person is 'OFF' their medications are not working as well or not at all. This is when their symptoms will be more noticeable. They may have a poor level of function and difficulty attending to their daily needs and activities.



### What if a person with Parkinson's falls?

If a person with Parkinson's does fall while you are with them you MUST respond according to your organisation's policies and procedures. Do not try and grab the person who has fallen as you may injure them or yourself.

The following may assist the person who has fallen to recover independently:

- Remain Calm
- Reassure your client
- Check for injury if you suspect your client has sustained an injury STOP call 000 for an ambulance
- If your client is unable to get up from a fall call an ambulance
- Follow your Organisation's Policies and Procedures.



### Falls

Falls can be a problem for everyone as they get older or have health problems. People with Parkinson's are also at risk of falls, which increases as the disease progresses.

There are a number of factors that increase the risk of falling:

- Freezing
- Small unsteady steps (shuffling)
- Dragging of foot or feet
- Stooped posture
- Posture, leaning to one side
- Dyskinesia, involuntary motor movements
- Postural instability
- Chronic illness
- Depression
- Anxiety
- Continence problems (urgency, frequency and incontinence)
- Side effects of medication
- Fatigue
- Sleep deprivation

Other factors that are often associated with falls include inappropriate footwear, loose clothing, clothing that is too long or too tight, dressing gowns cords, alcohol consumption and not using walking aids or trip hazards such as uneven surfaces like cracked footpaths, scatter mats, spills, pets, toys and poor lighting.

Knowing the risks associated with falls can help to assist in preventing them. It is important to make the person with Parkinson's aware of the risks and always encourage them to use their walking aids if recommended.

All falls need to be reported to the person's family or carer and your manager so that a record is kept.

# What treatments are available to people with Parkinson's?

## Types of treatment for Parkinson's include:

#### Apomine/Apomorphine

A drug that mimic the action of dopamine, is delivered by injection subcutaneously, similarly to insulin. It may be used as rescue drug, as it reliably works within 5-10 minutes, relieving some of the symptoms for approximately an hour. Apomorphine can also be delivered by continuous infusion. A butterfly needle is inserted and secured, usually in the abdomen and attached to a syringe driver which slowly and continuously delivers the medication. This procedure is normally completed by carer/spouse after the person with Parkinson's morning shower. In some instances arrangements are made with the Community Nursing Services.

#### Duodopa

Duodopa is delivered directly into the small intestine via a PEG-J tube (a tube passing directly into the stomach with an inner tube leading to the small intestine). Here it is absorbed in to the body. Delivery this way provides the brain with a continuous supply of dopamine. This method has been effective in improving quality of life in advanced Parkinson's for suitable candidates.

### **Deep Brain Stimulation**

Deep Brain Stimulation (DBS) - is a reversible therapy, whereby a thin, insulated lead is surgically placed into an area of the brain and is then connected via an extension to a small device called a neurostimulator. The neurostimulator is usually implanted under the skin the chest much like a cardiac pacemaker. When switched on the neurostimulator produces electrical impulses sent to the brain to stop or reduce some of the motor symptoms of Parkinson's, example, tremor. Although medication is still required it is usually at much lower doses.

None of these treatments are a cure or stop the progression of the Parkinson's but do assist in managing the disease. For further information on medications and treatments contact Parkinson's NSW Information Line on 1800 644 189,

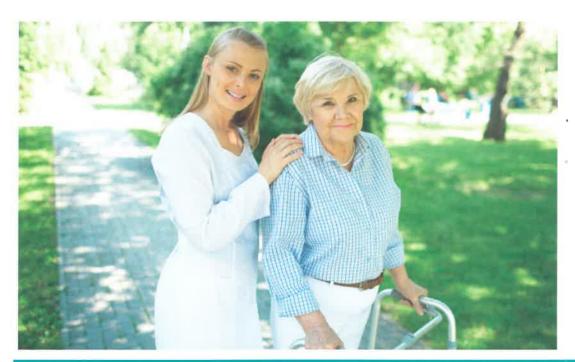
www.parkinsonsnsw.org.au or email pnsw@parkinsonsnsw.org.au

There are many signs and symptoms typical of Parkinson's. People with the diagnosis of Parkinson's don't necessarily have all the symptoms that are mentioned, however, they may have a combination of some of the symptoms. It is important that you are aware of most of the signs and symptoms so that individual care needs can be met. Also as the disease progresses you can more confidently report back to your manager.

A person with Parkinson's may have days when their symptoms are less severe than other days. This can occur for a number of reasons, such as, a change in medication, progression of the disease, poor sleep, or life events.

People with Parkinson's will have good and bad days, Parkinson's is unpredictable and varied, and therefore a person can change from hour to hour, minute to minute. To adequately meet the care needs of people with Parkinson's a degree of flexibility is required both within the organization and the care worker through ongoing communication

The following information provides practical tips to assist you while you are working with people with Parkinson's:



# **Care considerations**

## Mobility

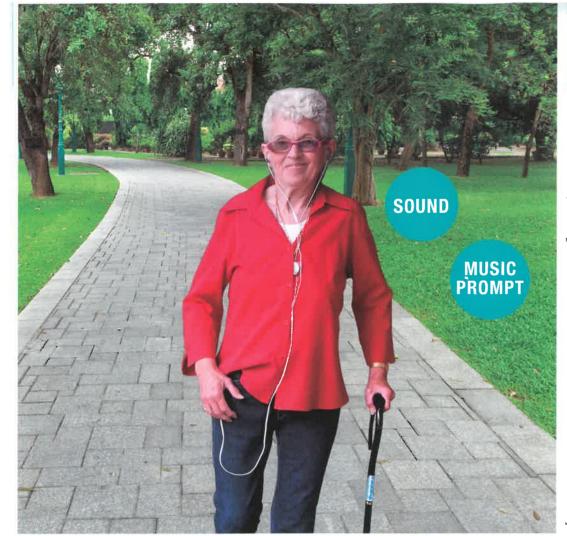
Parkinson's can have severe effects on mobility. This can be managed effectively by asking the person with Parkinson's to focus on the movement that they need to perform. This will help to cue or prompt the area of the brain not affected by Parkinson's to act.

### Freezing

Freezing, commonly referred to as freezing of gait, is when a person with Parkinson's stops as if their feet become stuck to the ground and they are unable to move. This can occur at any time including when they get to a doorway, are in the middle of a shopping centre or in a crowd, are changing from different floor surfaces, are turning or when they are taking the first step.

There are different types of cues that you can consider using when helping a person with Parkinson's:		
Think	Suggest counting steps either silently to themselves or out loud: 1, 2, 1, 2, 1, 2	
Visualise	Pretend to go up steps	
Visual	Lines on the floorboards carpet or tiles	
Sound	Suggest playing music that a person with Parkinson's can walk in time to and follow the beat	
Movements	Suggest shifting weight from one side to the other	

Cues can be used at any time and be helpful when medication is not working as well as normal or in stressful situations. The more time you spend with the person with Parkinson's, the more you will be able to anticipate when difficulty with mobility may occur.



### Time of visit

Some people with Parkinson's may have a period of time during the day when they are at their best. It may be helpful to see them during this time so that they will get maximum benefit from your visit. It is important to remember this time may change and over time you need to be flexible with your appointments.

## **Practical challenges**

Every organisation and employer has policies in regard to assisting clients. You MUST read and follow your organisation's policies. Particularly in reference to falls and other emergencies.

You may however find the following tips useful when overcoming the practical challenges that Parkinson's can present:







### Communication

Communication is possibly the most important aspect of your work. Not only will you be communicating with the person with Parkinson's, but also need to communicate with their family members which may include their husband, wife, sons and daughters.

It is important to remember that in most instances the person with Parkinson's and their family/carers have been dealing with the disease for many years and often knows what works and what doesn't.

Report back to your manager if you are unsure or if you notice any changes.

It is important to note that some people do not like to be called carers and like to be referred to as a family member only.

Possible challenges a person with Parkinson's may have in communicating are:

- Loss of speech, pitch and tone
- Rate of speech may be fast or slow
- Stuttering repetition of sounds, words or phrases
- Slurred speech
- Difficulty initiating speech
- Reduced facial expression
- Losing track of the conversation

A person with Parkinson's may also have what is called 'slowness of thought'. This is caused when the signals from the brain are slowed down. It may take people with Parkinson's longer to respond and form words.

### How can you help?

Speech difficulties can be embarrassing for a person with Parkinson's and will be a contributing factor in a person becoming isolated.

It may be helpful to find a quiet place, turn the television or radio down, face the person you are talking to and place yourself at the same level. If you don't understand what is said ask the person to repeat what they have said. You may have to ask them to slow down if they are speaking too fast or ask them to speak louder if they are speaking too softly. Often the person is unaware that they are speaking too softly or too fast. They may also be anxious particularly if at your first meeting so any speech problems may be heightened.

If you ask questions allow them time to respond to your question, remember they may need time to find the right words.

There are many ways to communicate these days and technology is progressing at ever increasing speed, your client may communicate by using a computer, word board, ipad, iphone, or tablet.

Remember everyone is different and unique.

