Parkinson's Disease

Issues for the Aged Care Team

Document prepared by:

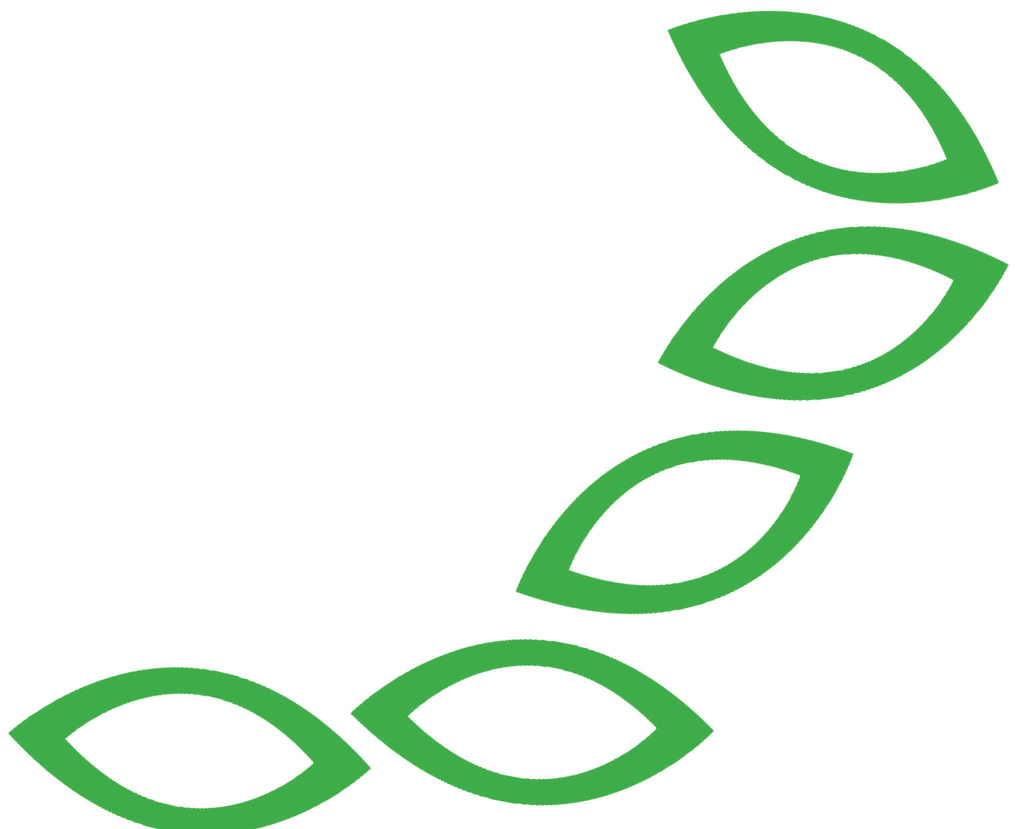
- Jane Turton, Progressive Neurological Diseases Program Manager, SMRPCC.
- Lee-Anne Henley, former Motor Neurone Disease Shared Care Worker & Other Progressive Neurological Conditions at SMRPCC
- Design: Jenny Stampe-Knox
- Layout: Penny Fletcher

Special thanks to:

Dr Jim Howe, Consultant Neurologist, Robert Wojnar, Pharmacist at Cabrini Hospital, and Victor McConvey, Fight Parkinson's, for their invaluable input and editing.

First edition — November 2022
Second edition — May 2024

Southern Metropolitan Region Palliative Care Consortium
https://smrpcc.org.au/



SMRPCC

Contents

Background 1
What is Parkinson's Disease? 1
What is Atypical Parkinson's Disease? 3
Parkinson's Disease motor symptoms 4
Parkinson's Disease non-motor symptoms 4
Pain 4
Nausea & vomiting 5
Agitation & delirium 5
Dysphagia 6
Sialorrhoea 6
Parkinson's Disease psychosocial needs 7
Support for the person with Parkinson's Disease 7
When to refer to specialist palliative care services? 8
Support for health professionals 8
Contact details for assistance 9
Example care plan — Aged Care Facilities 10

SMRPCC

Background

Many staff in Residential Aged Care Facilities (RACF) have cared for people with Parkinson's Disease, but less may have provided care for those with Atypical Parkinsonian syndromes: Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP), Corticobasal Syndrome (CBS) and Lewy Body Dementia. This document provides information about the relevant symptoms and care for people living with Parkinson's Disease. It also includes an example care plan that can be used as a guide for what should be addressed in a care plan.

Parkinson's Disease has a long trajectory and usually people come into aged care with advanced disease or with Parkinson's Disease as a co-morbidity. During the transition to the RACF, the resident will often lose contact with their neurologist. It is important to ensure this contact is maintained because there are important medication management issues to consider.

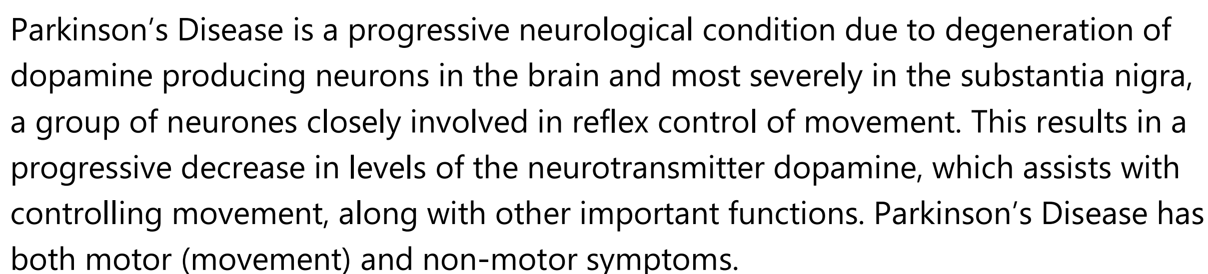
Several medications that are commonly used in symptom management will need to be substituted for people with Parkinson's Disease due to contraindications and possible worsening of Parkinson's symptoms. Furthermore, while many medications are rationalised during the terminal stage, all staff must know that sudden withdrawal of Parkinson's Disease medications (or inability to swallow the medication), may cause severe distress as a result of worsening motor and non-motor Parkinson's symptoms. Close collaboration with the treating neurologist is essential.

This package provides:

- Information and education about Parkinson's Disease and Atypical Parkinson's Disease (APD)
- A list of contacts and resources for health professionals
- An example care plan for a person with Parkinson's or Atypical Parkinson's Disease

What is Parkinson's Disease?

Parkinson's Disease is a progressive neurological condition due to degeneration of dopamine producing neurons in the brain and most severely in the substantia nigra, a group of neurones closely involved in reflex control of movement. This results in a progressive decrease in levels of the neurotransmitter dopamine, which assists with controlling movement, along with other important functions. Parkinson's Disease has both motor (movement) and non-motor symptoms.



The motor symptoms are tremor at rest (too much movement) and hypokinesia (too little movement), bradykinesia (slowness of movement), rigidity, poor balance & coordination.

Non-motor symptoms include fatigue, depression, anxiety, insomnia, autonomic disturbance such as bladder dysfunction, constipation, orthostatic hypotension, sialorrhoea (too much saliva), excessive sweating, pain, cognitive and memory problems, depression, delirium and psychosis. In the advanced/palliative care phase of these conditions, issues such as frequent falls, weight loss, development of pressure areas, infections leading to sepsis, swallowing & communication problems and delirium are common.

The average age of diagnosis is 55 - 65 years. However roughly one person in ten presents before age 50. Most people have no family history of Parkinson's. Genetic forms of Parkinson's do occur and more commonly affect people with young onset Parkinson's.

The progression of the disease leads to disability and increasing dependency on carers. Pharmacological treatment for motor and non-motor symptoms can become complex. Clinical issues are ongoing, and there is a need for timely and advance care planning and review.

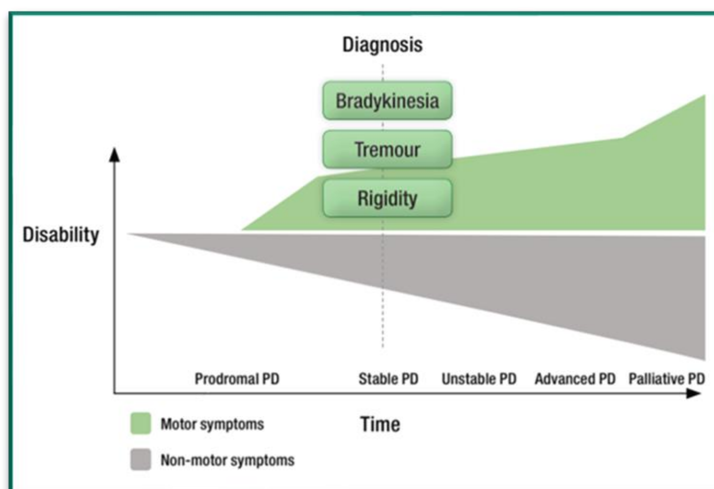


Figure 1: Graph showing the progression of both motor and non-motor symptoms over time (Research Review Educational Series Parkinson's Disease)

The range of symptoms means that a variety of health professionals including neurologists, pharmacists, speech therapists, occupational therapists and physiotherapists can be involved in the person's treating team, for best care. As the person transitions to RACF the treating team may change.

Timely referral to palliative care may be needed, due to the complex issues that arise at the end of life.

More people living with Parkinson's Disease now have Deep Brain Stimulators implanted. Careful liaison with the treating neurologist is essential to develop a plan for battery failure, which may include increased oral or transdermal medication. After death, the battery pack must be removed before cremation.

What is Atypical Parkinson's Disease?

Occasionally, a person with a diagnosis of Parkinson's Disease may have their diagnosis changed to one of the Atypical Parkinsonian Syndromes. Atypical Parkinsonian disorders are also progressive and generally present as Parkinson's Disease, however, over time, do not respond to Parkinson's medication.

The Atypical Parkinson's Diseases are rarer and include:

- **Multiple System Atrophy – MSA**
- **Progressive Supranuclear Palsy – PSP**
- **Corticobasal Syndrome – CBS**
- **Lewy Body Dementia – LBD**

Multiple System Atrophy – MSA - Along with the many similarities of Parkinson's Disease, people with MSA exhibit bladder muscle control issues resulting in incontinence and urinary retention. Also, low blood pressure resulting in dizziness and fainting. The major risk for people with MSA is falls with resulting head injuries.

Progressive Supranuclear Palsy – PSP - Also shares most of the similarities of Parkinson's Disease However, prominent features are loss of balance and tendency to fall backwards, and an inability to move eyes sideways or up or downwards. The visual changes impact on the person's ability to see where they are walking, read or engage effectively in conversations, or see what is on their dinner plates.

Corticobasal Syndrome – CBS – Symptoms include difficulty controlling the limbs on only one side of the body (called 'alien limb syndrome'), muscle spasms and jerkiness. Cognitive, visual and personality changes such as apathy and agitation are observed in CBS. Language difficulties, (dysphasia,) can be very severe.

Lewy Body Dementia – LBD – Presents with cognitive and memory impairment often with episodes of delirium and less marked motor symptoms.

SMRPCC

Parkinson's Disease motor symptoms

Motor symptoms in Parkinson's Disease can be treated with dopaminergic medications such as Levodopa, although the person may become less responsive to these medications over time. In late stages of Parkinson's Disease, the benefits of medication often wear off before the next dose is due and these times of hypokinesia/rigidity are called "off" states. This leads to increasing disability from rigidity, bradykinesia, tremor and pain, and is why involving the person's neurologist for medication review is beneficial. The pharmacist should also review other medications that can worsen Parkinson's Disease and cause rigidity.

In RACF, giving medications in a timely manner can sometimes be difficult. It is essential to give medications on time to people with Parkinson's Disease, RACF are encouraged to adopt processes to ensure adherence to correct medication administration occurs. The recommendation is to give Levodopa on an empty stomach (30 minutes before food, or 1 hour after food) for best absorption.
Note: Levodopa may be changed from tablet form to dispersible form if the person is unable to swallow tablets. Levodopa tablets should not be crushed.

Parkinson's Disease non-motor symptoms

Non-motor symptoms will be more evident during "off" periods. Noting when the person had their last dose of medication when assessing non-motor symptoms is important. Providing food and fluids will be easier during "on" periods.

Pain

- Pain may be musculoskeletal and relate to rigidity. Carefully assess to see if pain is associated with "off" time. Aim to give dopaminergic medications strictly on time.
- Consider careful positioning, massage, and physiotherapy.
- Immobility, rigidity, and weight loss can increase the risk of pressure injury over bony prominences, the sacrum and from contractures. The development of pressure injury is common. It is recommended to provide an alternating pressure mattress, if possible, to increase comfort, and decrease risk of pressure injury.
- Give analgesia prior to transfer and personal care, including repositioning, and before wound management if pressure injury has occurred. For pain from pressure injury, use routine oral analgesics; opioids may be required.

- If pain is due to rigidity which cannot be resolved, there may be a need to use midazolam (oral initially, or subcutaneous) or sublingual clonazepam for muscle relaxation.

Changed symptoms that trigger a progression towards the palliative stage of the illness include; a refractory pain, pain caused by infections, or pain caused by increasing immobility.

Nausea & vomiting

Nausea and vomiting are not a symptom of Parkinson's Disease, however if it occurs:

- Treat with Domperidone (Motilium®).
- Or Ondansetron (Zofran®) but this is contraindicated if the person is on apomorphine for Parkinson's Disease.
- There may be a role for alternative anti-emetics: cyclizine, or levomepromazine (use with caution). Consult with a palliative care physician & pharmacist for these options. Cyclizine can cause anticholinergic adverse effects which can worsen delirium.
- **Do not use Metoclopramide (Maxolon®), Haloperidol (Serenace®) or Prochlorperazine (Stemetil®) as they may exacerbate Parkinson's Disease motor symptoms.**

Triggers indicating a progression towards the palliative stage of the illness include; aspiration pneumonia, weight loss, inability to absorb medication, infection or a loss of appetite.

Agitation & delirium

- Assess for reversible causes of delirium.
- Review current medications (all Parkinson's Disease medications can cause and exacerbate delirium, especially when there is cognitive impairment). In the later stages of Parkinson's Disease there can be an increased sensitivity to dopaminergic medications causing hallucinations and delusions. These medications may also become less effective, and in consultation with the person with Parkinson's and their carers, may gradually be reduced.
- **Do not use haloperidol (Serenace®) as it may exacerbate Parkinsonian symptoms.**
- If client is able to swallow, quetiapine can be used.

- Hallucinations, — usually visual, are common in up to 60% of people living with Parkinson's Disease and may be more apparent, confusing, and frightening in advanced stages. Assess for intercurrent illness/causes (infection, constipation, pain, urinary retention, medication). Distressing and confusing hallucinations are often effectively managed using Quetiapine.
- Delusions and psychosis — paranoia, persecutory and marital infidelity are common delusions which occur in psychosis in Parkinson's Disease. Psychosis is treated by adding Quetiapine and reviewing Parkinson's Disease medications.
- Cognitive change and dementia — screening for cognitive change needs to be sensitive to "on" and "off" states and to the impact Parkinson's Disease has had on verbal and nonverbal communication.

Triggers indicating a progression towards the palliative stage of the illness include; increasing anxiety/depression, changed cognition, infection - aspiration, respiratory failure, and deteriorating cognition.

Dysphagia

- Affects up to 80% of people with Parkinson's Disease and can impede the swallowing of oral medications.
- Dysphagia will also increase the risk of aspiration pneumonia and a multidisciplinary approach is recommended:
  - occupational therapist to assist with modified eating equipment for independence
  - pharmacist to advise on the best formulation or method of medication administration
  - speech pathologist to assess swallow and recommend diet modification
  - dietician to monitor nutritional intake.

Triggers indicating a progression towards the palliative stage of the illness include; aspiration pneumonia, malnutrition/dehydration and loss of appetite and weight loss. Aspiration pneumonia is the leading cause of death in Parkinson's Disease.

Sialorrhoea

- Excessive saliva and drooling occur in Parkinson's Disease due to infrequent swallowing, poor oral motor control and autonomic dysfunction.
- Encourage regular swallowing.
- Apply a barrier cream to skin.

- Referral to speech pathologist.

Triggers indicating a progression towards the palliative stage of the illness include; aspiration pneumonia, choking and coughing – not necessarily during eating and drinking and increasing difficulty swallowing.

Parkinson’s Disease psychosocial needs

Depression, anxiety, fear of the future, role change, loss of independence, behavioural issues, communication difficulties, social isolation/stigma, financial strain, advance care planning and spiritual well-being are areas that may need to be addressed.

Stress experienced by family and significant others may become overwhelming as the disability caused by Parkinson’s Disease symptoms increases. Support for the significant others is vital even after admission to care.

Support for the person with Parkinson’s Disease

Fight Parkinson’s (formerly Parkinson’s Victoria) can be reached on Freecall Information Line **1800 644 189** (Monday to Friday 9 am to 5 pm) or at www.fightparkinsons.org.au and provides confidential support for the person with Parkinson’s Disease and their carers about:

- Medications
- Symptom management
- Treatment options
- Mobility equipment and disability aids
- Peer support
- Carer support
- Health events and seminars
- Health services and health professionals
- Resources and publications

Parkinson’s Australia has further information at: www.parkinsons.org.au

Community Palliative Care Services and Palliative Care Consultancy Services provide specialist support for complex psychosocial needs and symptom control for people with Parkinson’s Disease particularly in the end-of-life period.

GPs will remain responsible for primary health issues, in conjunction with specialist palliative care services.

SMRPCC

When to refer to specialist palliative care services?

It is important to continually assess for deterioration, as it helps plan for better care if the person needs specialist care or is entering a terminal stage of their disease progression.

For some people, the palliative approach might be enough, but others may require specialist palliative care. There is no one clear answer on when is the right time to refer a person to specialist palliative care. The trigger for a referral may be one of the points discussed in this document, or a combination of many symptoms.

The evidence does suggest that earlier referrals benefit the management of physical, emotional, spiritual and social needs. As palliative care is based on individual needs, some people will require periodic referrals to specialist palliative care services.

If in doubt, it's always worth calling your local palliative care service.

Support for health professionals

Fight Parkinson's can help health professionals develop a treatment or management plan for a person living with PD:

- 1800 644 189 Freecall Information Line for health professionals
- www.fightparkinsons.org.au

Fight Parkinson's also provides information and fact sheets:

- www.fightparkinsons.org.au/information-for-you/publications/#fact-sheets

Fight Parkinson's has a brochure about medications to be used with caution:

- Medications to be Used with Caution for People with Parkinson's

Parkinson's UK has an information booklet for nurses:

- Caring for your patient with Parkinson's - Information for ward staff

The Irish Palliative Care in Parkinson's Disease Group. (2016) *Palliative care in People with Parkinson's disease: Guidelines for professional healthcare workers on the assessment and management of palliative care needs in Parkinson's disease and related Parkinsonian syndromes*. Cork: University College Cork.

SMRPCC's resource Consider the Carer helps health professionals reduce carer burden.

Contact details for assistance

Fight Parkinson's	www.fightparkinsons.org.au	1800 644 189
Parkinson's Australia	www.parkinsons.org.au	1800 644 189
Progressive Neurological Diseases Program Manager, SMRPCC	jane.turton@smrpcc.org.au	0428 264 446
The Palliative Care Advice Service	www.pcas.org.au	1800 360 000

SMRPCC

Example care plan — Aged Care Facilities

This care plan was developed with the assistance of Carol Barbeler, Palliative Aged Care and Disability Resource Nurse & MND Shared Care Worker (Gippsland), Gippsland Region Palliative Care Consortium.

Domain	Goal	Required Assessment / Action	Alerts / Red Flags
Advance Care Planning	• Discuss and complete an Advance Care Directive (ACD) or Advance Care Plan (ACP) on admission to ACF, if it has not been undertaken prior to admission (review if previously completed) • Medical Treatment Decision Maker identified • Client and carer discussion and review of ACD/ACP with episodes of deterioration and support	• Is the resident/ representative aware of the diagnosis and prognosis? • Future communication difficulties are expected, and resident's wishes regarding medical interventions need to be documented. Have appropriate documents been completed? • Advance Care Directives (ACD) • Goals of Care (GOC) • Medical Treatment Decision Maker (MTDM) forms etc. • Document evidence of any communication/ case conferences, areas of care discussed, document actions	• Representatives have a poor understanding of prognosis (arrange meeting with appropriate staff to explore further) • Deterioration in communication and/or cognition may already have occurred. MTDM/ family will be required to act in substitute decision maker role

SMRPCC

Domain	Goal	Required Assessment / Action	Alerts / Red Flags
		• Review goals of care regularly, and with changes to each phase of illness	
Communication	• Ensure the resident's current method of communication is understood and taught to all staff • Resident's needs and preferences are clearly understood by all staff involved in care • Identify signs of decline/ deterioration and refer to appropriate allied health for action • Fatigue is recognised, and reduced • The client feels supported, listened to and is able express their personality, values and wishes	• Is the resident able to verbalise? If so, how much? • Preferred language interpreter required? • Ensure that the current forms of communication are known, documented, and conveyed to care team. • Ensure those in contact with the resident are taught how to communicate with the person with Parkinson's Disease and in their preferred mode. • Regular assessment and treatment with speech pathologist and neuropsychologist assessment if cognition is affected	• Decrease in ability to speak clearly or use communication aids (refer to Speech Pathologist) • Changes in cognition and language occur with the development of Lewy Body Dementia • Consider delirium if changes to behaviour or communication have a sudden onset

Domain	Goal	Required Assessment / Action	Alerts / Red Flags
		• Ensure glasses and hearing aids are fitted, clean & working • Consider consult with speech pathologist to introduce alternate communication methods if needed	
Pain and spasm	• Identify possible and reversible causes of pain • Aim for improvement to level of comfort acceptable to the person • Regular evaluation & review	• Assess for cause (musculoskeletal, pressure injury, dystonia, neuropathic pain, muscle spasm, comorbidities) • Prioritise Parkinson's Disease medications, on time • Appropriate non-pharmacological treatments, (massage, exercise, positioning, equipment to reduce pressure risk) • Analgesics as prescribed, with regular review, including breakthrough and incident pain management	• Increasing pain/spasm • Acute onset of pain/new pain

SMRPCC

Domain	Goal	Required Assessment / Action	Alerts / Red Flags
Nutrition and Hydration	• Ensure resident's nutritional status is maintained • Recognise and respond to dietary/fluid intake issues promptly, and consistent with ACP/GOC • Ensure all care staff have adequate training and aware of person's method of eating and drinking (thickened fluids and moist/minced/pureed diet?) (IDDSI Framework)	• Monthly weight monitoring • Ensure resident is provided with appropriate food and fluid thickness (use IDDSI framework). • Provide assistive devices used (2 handled mug, plate guard, assistive cutlery etc consistent with allied health assessment – OT • Amount/ type of assistance required – e.g.: sitting upright during meals and 30 minutes post feed, staff assist with feeding; teaspoon used for feeds, double swallow between mouthfuls, do not rush feeding etc. • Dietary supplements may be required. Ensure type, amount, and frequency is assessed and reviewed by dietitian	• Weight loss or gain • Any change to/ difficulty swallowing, coughing, or choking refer to speech pathologist • Episode of aspiration pneumonia refer to speech pathologist

Domain	Goal	Required Assessment / Action	Alerts / Red Flags
		• Refer to allied health professional as needed for re assessment with change of health status, or change to weight	
Manage secretions	• Residents' secretions are monitored and minimised for comfort and dignity • Medication to manage secretions is given on time and effectiveness reviewed	• Document and describe secretion patterns and symptoms/ any distress • Review by speech pathology and medical team, as needed. • Non-pharmacological treatment methods described including positioning, use of dignity garments to protect clothes • Refer to mouth/ skin care plans for specific detail	• Drooling, increase in secretions, aspiration pneumonia/ chest infections to be reviewed by treatment team • Current medication regime no longer working – refer to GP/ treatment team.
Mobility	• Resident is assisted to maximise their independence • Risks related to mobility are assessed and managed consistent with GOC/ACP	• Falls Risk Assessment undertaken on admission, and reviewed with change to health status • Implement falls risk minimisation strategies as appropriate/ consistent with GOC/ACP	• Changes in the resident's mobility or transfer status is referred to the physiotherapist for assessment/ management • Falls and near misses

SMRPCC

Domain	Goal	Required Assessment / Action	Alerts / Red Flags
	• Deterioration of functionality is identified and referred to the appropriate treatment team member, response is consistent with GOC/ACP	• Appropriate footwear • Level of assistance/ supervision • Bed height (including floorline bed usage) • Sensors required • Frequency of supervision • Aids used to assist with mobility (frames, walkers wheelchairs, electric beds, princess chair etc.) are reviewed by allied health, with change of health status, and as required • Does the room need to be "set up" in particular way to enhance independence? **Transfers:** • Number of staff required, and equipment needed– (sling or standing lifter, transfer sheets, overhead assistive devices, tiger tails etc.)	• Changes in physical capacity are to be referred to the treating team

SMRPCC

Domain	Goal	Required Assessment / Action	Alerts / Red Flags
		• Any therapeutic regime/ exercises are enabled as per the care plan	
Hygiene	• Residents level of personal hygiene are maintained, respecting resident preferences, abilities and comfort	**Personal Hygiene** • Frequency/ preferences/ preferred timing of assistance/ level of assistance required including number of staff • Analgesia is offered before hygiene activities. Products used (include preferred soaps, shampoo, moisturiser, shaving/ epilation etc) • Mouth Care/ oral and dental assessment/ care • Importance of positioning	• Skin tears, bruises or suspected pressure injury • Oral pain, discomfort or difficulty with eating • Ineffective management of secretions
Skin Care	• Skin is maintained in optimal condition • Risks to skin integrity are identified, and strategies	• Skin Care Assessment and risk assessment – undertaken, on admission, and with change of health status/ as required	• Refer to treating team, wound specialist as required

Domain	Goal	Required Assessment / Action	Alerts / Red Flags
	used to minimise injuries/wounds	• Daily review/ check of pressure areas – skin condition • Recognise and respond to any skin irritation, pressure injury, skin tears, wounds, bruises, excoriation, consistent with GOC/ACP • Use preferred skin care products and frequency of use	
Elimination	• Residents comfort and dignity is maintained • Constipation is prevented or managed appropriately • Indwelling urinary catheters (IDC) are managed appropriately	• Continence Assessment completed • Continence plan developed • Toileting times and level of assistance identified • Continence aid and toileting schedule implemented/review with change to health status/as required • IDC/SPC • Catheter type, size and frequency of change	• Change in level of continence • Elevation in temperature, urine colour/ odour or amount • Evidence of delirium • Monitor bowel activity daily and report if BNO for 2 days to follow management plan report to RN in charge

Domain	Goal	Required Assessment / Action	Alerts / Red Flags
		• Bag usage for day and night described • Stoma care clearly documented **Bowel** • Monitor bowel activity each shift and identify usual routine (i.e., BO every 2-3 days) • Implement bowel management strategies including dietary requirements (fibre and fluids), aperient usage • Use of suppositories/ enemas (including usual frequency of use and preferred brands) • If opioids used in pain management plan, aperient must be administered daily, not PRN	
Behaviour	• Behaviours of concern are identified and managed effectively (apathy, agitation, sleep	• Monitor resident for any specific behaviours of concern and document risk minimisation strategies	• Refer to treating team for review • Refer to GP for mental health care plan

Domain	Goal	Required Assessment / Action	Alerts / Red Flags
	disturbances, hallucinations, depression) • Residents' cognitive function and wellbeing is monitored	• Report any evidence of low mood/ anxiety including apathy, sadness, crying, fear, insomnia, excessive sleeping, refusal to leave room, expressions re: dissatisfaction with quality of life and/ or desire to die statements • Recognise and respond to acute changes/escalation in level of confusion, consistent with delirium	• Acute increase in level of confusion • Poor pain management which may increase expressions of behaviour • Erratic, bizarre behaviour, consistent with Lewy Body Dementia • Aged persons mental health team if appropriate

The recording of data on a care plan will be in accordance with the practices and documentation of each Aged Care Facility.

Treating Team		
Team Member	**Name and Contact Details**	**Hours of Work / Availability**
General Practitioner		
Neurologist		
Palliative Care Team		
Residential In-Reach Team		
Dietician		
Physiotherapist		
Wound Specialist		
Other		

Equipment	Supplier	Repairer Details
Wheelchair		
Communication Aids		
Other		