



# Parkinson's Disease

## Issues for the Palliative Care Team

# Contents

1. What is Parkinson’s Disease? .....	1
2. PD Motor Symptoms .....	2
3. PD Non-Motor Symptoms Towards EOL .....	3
4. PD Psychosocial Needs .....	5
5. Support for the Person with PD and their Carers.....	5
6. Support for Health Professionals when Working with PD .....	5
7. Contact Details for Assistance .....	6
8. Parkinson’s Disease (PD) Example Care Plan.....	7

**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.



# Parkinson's Disease

## Issues for the Palliative Care Team

---

The palliative care team may be asked to manage end of life Parkinson's Disease symptoms, especially in Residential Aged Care Facilities. At other times palliative care staff are caring for people with terminal illnesses who also have Parkinson's Disease (PD) as a comorbidity.

Several medications that are commonly used in terminal symptom management will need to be substituted for people with PD due to contraindications and possible worsening of Parkinson's symptoms. Furthermore, whilst many medications are rationalised during the terminal stage, staff must be aware that sudden withdrawal of PD medications (or inability to swallow), may cause distressing worsening of both motor and non-motor PD symptoms. Close collaboration with the treating neurologist is essential.

This package is designed with summary information to help staff care for people with PD in the terminal stage, and their family/carers. It includes contact details for further help and information. The example care plan is designed to be a prompt for the kinds of issues that should be included in a comprehensive care plan.

### 1. What is Parkinson's Disease?

PD is a progressive neurological condition which occurs from degeneration of dopamine producing neurons within the part of the brain called the substantia nigra. This results in a progressive decrease in levels of the neurotransmitter dopamine, which assists with controlling movement. PD 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, excessive sweating, pain, cognitive and memory problems, depression, psychosis, and Lewy Body Dementia. In the palliative stages, issues such as frequent falls, weight loss, development of pressure areas, infections leading to sepsis, swallowing & communication problems are common.

The average age of diagnosis is 55 - 65 years. However, 10% of incidence occurs in people 50 and under. Most people have no familial history of Parkinson's. Genetic forms of Parkinson's do occur and 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 advance care planning.

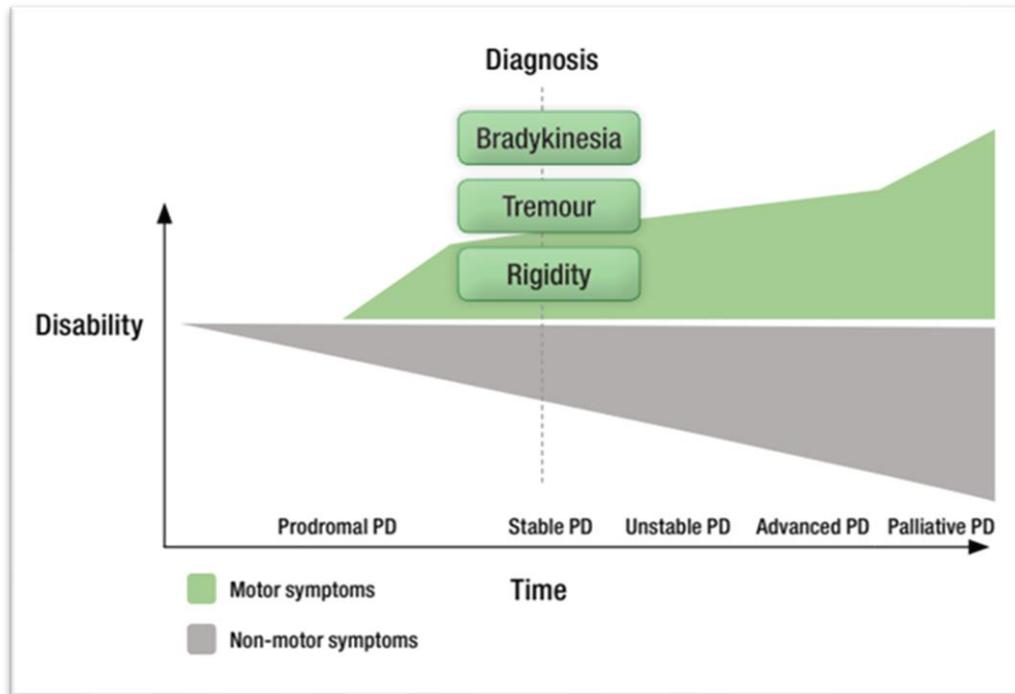


Figure 1: Graph showing the progression of both motor and non-motor symptoms over time  
([Research Review Educational Series Parkinson's Disease](#))

- The range of symptoms means that a variety of health professionals including neurologists, pharmacists, speech, occupational and physiotherapists should be involved in the person's team, for best care.
- Timely referral to palliative care is important, due to the complex issues that arise. These may include symptom management, cognitive impairment, legal and financial issues, care giver stress, and equipment needs.
- More people living with PD 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.

## 2. PD Motor Symptoms

Motor symptoms in PD 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 PD, the benefits of medications 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 PD and cause rigidity.

It is essential to ensure medications are given strictly on time and to continue oral medications for as long as possible. The recommendation is to give Levodopa on an empty stomach (30 minutes before food, or 1 hour after food) for best absorption. Note that Levodopa may be changed from tablet

form to dispersible form if the person is unable to swallow tablets. Levodopa tablets should not be crushed.

In palliative stages when swallowing even liquid medications may be difficult, an alternative form of administration needs to be considered, in consultation with the neurologist or geriatrician and pharmacist, such as a rotigotine patch (Neupro®) or subcut apomorphine. Levodopa and other medications used to treat Parkinson's should not be suddenly stopped. This may cause severe worsening PD symptoms and it can cause fever, muscle rigidity, sweating, tachycardia and agitation.

In the terminal stage, rigidity may be treated with subcut midazolam or subling clonazepam when dopaminergic medications are no longer being used.

### 3. PD Non-Motor Symptoms Towards EOL

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

End-of-life Anticipatory Prescribing Recommendations are available on the NSW Government Clinical Excellence Commission website as part of the [Last Days of Life Toolkit](#).

See the following link for end-of-life Anticipatory Prescribing Recommendations:

[Last Days of Life ANTICIPATORY PRESCRIBING RECOMMENDATIONS](#)

#### Pain

- Pain may be musculoskeletal and relate to rigidity. Carefully assess to see if pain is associated with "off" time. Give dopaminergic medications strictly on time.
- Consider careful positioning, massage, and physiotherapy.
- Immobility, rigidity, and weight loss can increase the risk of pressure areas over bony prominences, the sacrum and from contractures. Painful pressure ulcers are common towards EOL. Provide an alternating pressure mattress, if possible, to increase comfort, and decrease risk of pressure areas developing.
- Give analgesia prior to pressure area care. For pain from pressure areas use routine oral analgesics, and 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 subcut) or subling clonazepam for muscle relaxation.

#### Nausea & vomiting

- Treat with domperidone (Motilium®).
- Or treat with ondansetron (Zofran®) but this is contraindicated if the person is on apomorphine for PD.
- 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 PD symptoms.**

## Agitation & delirium

- Assess for reversible causes of delirium.
- Review current medications (all PD medications can cause and exacerbate delirium, especially when there is cognitive impairment). In the later stages of PD 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 PD and their carers, may gradually be reduced.
- **Do not use haloperidol (Serenace®) as it may exacerbate PD symptoms.**
- If client is able to swallow, quetiapine can be used.
- If nil orally, and for terminal care, consider subcut midazolam (first line) or low dose subcut levomepromazine (second line, not TGA registered but available via the Special Access Scheme).
- For terminal sedation, Phenobarbitone can be used safely.
- Hallucinations — usually visual, are common in up to 60% of people living with PD and may be more apparent, confusing and frightening in advanced stages. Assess for intercurrent illness. 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 PD. Psychosis is treated by adding quetiapine and reviewing PD medications. Medications such as COMT inhibitors, MAO-B inhibitors and dopamine agonists may be reduced and ceased by the neurologist.
- Cognitive change and dementia — screening for cognitive change, needs to be sensitive to “on” and “off” states and to the impact PD has had on verbal and nonverbal communication.

## Dysphagia

- Affects up to 80% of people with PD and can impede the swallowing of oral medications. Early monitoring in the palliative stages allows for substitute delivery of PD medications, for example: via rotigotine patch or intestinal levodopa infusion or subcut apomorphine.
- 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.

## Sialorrhea

- Excessive saliva and drooling occur in PD due to infrequent swallowing, poor oral motor control and autonomic dysfunction.
- Encourage regular swallowing.
- Apply a barrier cream to skin.
- Give frequent mouth swabbing.
- Referral to speech pathologist.
- Glycopyrrolate 1-2 mg by mouth TDS or Regular oral or subcut hyoscine butylbromide.
- Hyoscine butylbromide infusion may be used for terminal care.

## 4. PD 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 by Palliative Care services.
- Caregiver stress may become increasingly overwhelming as the disability caused by PD symptoms increases. Support for the carers will assist the person with PD to remain at home for longer.
- Two websites that offer support, information, resources, and local services to carers are:
  - Carers Victoria [www.carersvictoria.org.au](http://www.carersvictoria.org.au)
  - Carers Gateway [www.carergateway.gov.au](http://www.carergateway.gov.au)

## 5. Support for the Person with PD and their Carers

- Fight Parkinson's (Victoria) can be reached at [www.fightparkinsons.org.au](http://www.fightparkinsons.org.au) or on Freecall Information Line **1800 644 189** (Monday to Friday, 9 am to 5 pm) for confidential support and health information 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 website has further information [www.parkinsons.org.au](http://www.parkinsons.org.au)
- Community or Hospice Palliative care provides specialist support for complex psychosocial needs and symptom control of people with PD particularly at end of life.
- Respite services and home care services can assist with daily and routine care and help to relieve carer burden.
- GPs are a valuable source of support in the community.
- Financial planners and solicitors can provide assistance with future planning.

## 6. Support for Health Professionals when Working with PD

- Fight Parkinson's (Victoria) 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](http://www.fightparkinsons.org.au)
- Fight Parkinson's (Victoria) also provides information and fact sheets:
  - [www.fightparkinsons.org.au/information-for-you/publications/#fact-sheets](http://www.fightparkinsons.org.au/information-for-you/publications/#fact-sheets)
- Fight Parkinson's (Victoria) has a brochure about medications to be used with caution:
  - [Medications to be Used with Caution for People with Parkinson's](#) brochure
- Parkinson's UK has an information booklet for nurses:

- [Caring for your patient with Parkinson's - Information for ward staff](#)
- SMRPCC's resource [Consider the Carer](#) helps health professionals reduce carer burden.

## 7. Contact Details for Assistance

Fight Parkinson's	1800 644 189	<a href="http://www.fightparkinsons.org.au">www.fightparkinsons.org.au</a>
Parkinson's Australia	1800 644 189	<a href="http://www.parkinsons.org.au">www.parkinsons.org.au</a>
The Palliative Care Advice Service	1800 360 000	<a href="http://www.pcas.org.au">www.pcas.org.au</a>

## References

- Caresearch, Prescribing considerations at the end of life, viewed 12 July 2022, <<https://www.caresearch.com.au/tabid/6314/Default.aspx>>
- Kluger, B. M., Shattuck, J., Berk, J., Sebring, K., Jones, W., Brunetti, F., Fairmont, I., Bowles, D. W., Sillau, S., & Bekelman, D. B. (2018), *Defining Palliative Care Needs in Parkinson's Disease*, *Movement Disorders Clinical Practice*, 6(2), 125–131, viewed 12 July 2022, <<https://doi.org/10.1002/mdc3.12702>>
- National Collaborating Centre for Chronic Conditions (UK), (2006), *Parkinson's Disease: National Clinical Guideline for Diagnosis and Management in Primary and Secondary Care*, Royal College of Physicians (UK).
- Parkinson's disease in adults, NICE guideline, viewed 12 July 2022, <<https://www.nice.org.uk/guidance/ng71/chapter/Recommendations#palliative-care>>
- Palliative Care Expert Group, *Therapeutic Guidelines: Palliative Care*, 2016 Version 4, Therapeutic Guidelines Limited: Melbourne
- Sellbach, A., & Silburn, P. (2012), *Management of Parkinson's disease*, *Australian Prescriber* 2012;35:183–8
- Wilcock A, Howard P and Charlesworth S., *Palliative Care Formulary*, 7<sup>th</sup> edition, London, 2020, Pg 701-702

## 8. Parkinson's Disease (PD) Example Care Plan

- This care plan was developed with the assistance of Carol Barbeler, Palliative Aged Care & Disability Resource Nurse GRPCC.

	Care Issue	Action Plan	Desired Outcome
1.	Discuss an <b>Advance Care Plan</b> before deterioration in communication makes it difficult to ascertain patient wishes	<ul style="list-style-type: none"> <li>Discuss with client and arrange access to assistance to complete documentation</li> <li>Offer a discussion starter such as <a href="http://palliativecare.org.au/campaign/what-matters-most-for-older-australians">palliativecare.org.au/campaign/what-matters-most-for-older-australians</a> to start the advance care planning process</li> <li>Access to relevant medical, legal and financial and counselling services as required</li> <li>Review goals of care regularly, and with changes to each phase of illness</li> </ul>	<ul style="list-style-type: none"> <li>Client's wishes known and documented and distributed</li> <li>Medical treatment decision maker identified</li> <li>Legal and financial issues addressed</li> <li>Client and carer education and support</li> </ul>
2.	<b>Pain</b> (Commonly muscular skeletal from limited mobility and muscle spasms)	<ul style="list-style-type: none"> <li>Assess for cause, musculoskeletal, pressure ulcer, dystonia, neuropathic pain,</li> <li>Dopaminergic medications on time</li> <li>Appropriate non analgesic treatment, massage, exercise, positioning, equipment to alleviate pressure</li> <li>Analgesics as prescribed with regular review</li> </ul>	<ul style="list-style-type: none"> <li>Cause identified</li> <li>Optimal pain control</li> <li>Regular assessment</li> </ul>
3.	<b>Agitation &amp; delirium, hallucinations</b>	<ul style="list-style-type: none"> <li>Investigate cause of delirium</li> <li>Monitor dopaminergic antiparkinson drugs with pharmacist for adverse SE of medications</li> <li>Treat underlying causes i.e. constipation, pain, infection</li> <li>Avoid antipsychotic medication</li> <li>Low dose quetiapine 25mg D or BD (Palliative Care Therapeutic Guidelines P174)</li> <li>Terminal stage - levomepromazine or midazolam S/C</li> </ul>	<ul style="list-style-type: none"> <li>Reversible causes investigated &amp; treated</li> <li>If needed, withdrawal/reduction of dopaminergic medications done gradually in conjunction with neurologist &amp; pharmacist</li> <li>Optimal symptom management</li> <li>Safe medication regime</li> </ul>

## Parkinson's Disease (PD) Example Care Plan

	Care Issue	Action Plan	Desired Outcome
4.	<b>Nausea &amp; vomiting</b>	<ul style="list-style-type: none"> <li>▪ Regime of hydration and nutrition as tolerated</li> <li>▪ Avoid medications that exacerbate rigidity</li> <li>▪ Domperidone 10mg po 8/24 (Palliative Care Therapeutic Guidelines p265)</li> <li>▪ Discuss role of ondansetron, or cyclizine with doctor &amp; pharmacist</li> </ul>	<ul style="list-style-type: none"> <li>▪ Adequate hydration &amp; mouth care</li> <li>▪ Regular symptom assessment &amp; management</li> <li>▪ Safe medication regime for PD</li> <li>▪ Quality of life enhanced</li> </ul>
5.	<b>Dysphagia</b>	<ul style="list-style-type: none"> <li>▪ Ensure there are alternate routes for medications to be administered to maintain symptom control i.e. dispersible tablets, transdermal or subcut routes</li> <li>▪ Speech therapist for assessment &amp; dietary, thickened fluids &amp; swallowing advice.</li> <li>▪ Rationalisation/deprescribing of non-essential oral medications</li> </ul>	<ul style="list-style-type: none"> <li>▪ Choking risk mitigated</li> <li>▪ Alternate route for medications</li> <li>▪ Pre-emptive prescribing</li> <li>▪ Safe swallowing practices</li> <li>▪ Nutrition &amp; hydration maintained where possible and quality of life enhanced</li> </ul>
6.	<b>Recurrent infections/sepsis risk</b>	<ul style="list-style-type: none"> <li>▪ May commonly occur in the deteriorating and terminal stage, assess for cause, UTI, pneumonia, pressure ulcer, increasing frailty.</li> <li>▪ Antibiotic treatment as per advance care wishes</li> <li>▪ Pressure area care, maintain skin integrity, pressure relieving aids, manage incontinence.</li> <li>▪ Pressure ulcer care, appropriate dressings, odour &amp; bleeding strategies in place</li> <li>▪ Analgesia, regular &amp; for incident pain, prior to dressing change</li> <li>▪ Review goals of care and ACP to ensure wishes are still relevant and appropriate</li> </ul>	<ul style="list-style-type: none"> <li>▪ Infection assessed and cause treated appropriately according to clients ACP</li> <li>▪ All comfort measures given.</li> <li>▪ Appropriate analgesia given with regular pain assessment</li> </ul>

## Parkinson's Disease (PD) Example Care Plan

	Care Issue	Action Plan	Desired Outcome
7.	<b>Manage secretions/ sialorrhea</b>	<ul style="list-style-type: none"> <li>▪ Regularly assess &amp; document secretion patterns and symptoms, thick or thin, excessive saliva or dry mouth</li> <li>▪ Encourage frequent swallowing of excess saliva, frequent wiping /swabbing of secretions, position head to promote drainage, protect skin surrounding mouth, protect clothing</li> <li>▪ Consider anticholinergic medication to dry secretions if they are excessive &amp; distressing (anticholinergics may cause confusion)</li> <li>▪ For a dry mouth, increase hydration, apply oral lubricants</li> </ul>	<ul style="list-style-type: none"> <li>▪ Secretions monitored, symptoms managed.</li> <li>▪ Any medications to dry up saliva must be monitored for S/E of dry mouth &amp; thick tenacious secretions and increasing confusion</li> <li>▪ Client and carer education and support for mouth hygiene regime</li> <li>▪ Access to speech pathologist and medical services for information on how to manage secretions, drooling</li> </ul>
8.	<b>Bladder dysfunction</b> (Urine retention & urinary irritability)	<ul style="list-style-type: none"> <li>▪ Monitor for UTI</li> <li>▪ Monitor for increased confusion or agitation towards EOL</li> <li>▪ Bladder scan if available to assess for retention</li> <li>▪ Catheterisation may be necessary with urinary retention</li> </ul>	<ul style="list-style-type: none"> <li>▪ Urinary continence promoted, output monitored</li> <li>▪ UTI identified early and antibiotics commenced</li> <li>▪ Retention excluded or managed with catheter</li> </ul>
9.	<b>Constipation or bowel changes</b>	<ul style="list-style-type: none"> <li>▪ Access to physiotherapy re mobility assistance and safety in toileting</li> <li>▪ Monitor bowel function to meet client's usual pattern</li> <li>▪ Regular review by dietician for dietary fibre and fluids</li> <li>▪ Aperients and suppositories as medically required</li> </ul>	<ul style="list-style-type: none"> <li>▪ Use of aids and equipment and appropriate transfers to ensure mobility and safety for toileting</li> <li>▪ Adequate hydration and nutrition</li> <li>▪ Monitor side effects of drugs</li> <li>▪ Regular bowel motions/avoid constipation</li> </ul>

## Parkinson's Disease (PD) Example Care Plan

	Care Issue	Action Plan	Desired Outcome
10.	<b>Mobility</b>	<ul style="list-style-type: none"> <li>▪ Referral and assessment with the physiotherapist/occupational therapist for relevant equipment and assistive technology</li> <li>▪ Liaise with appropriate agencies to ensure home modification, equipment and funding is arranged according to needs.</li> <li>▪ Carer and client education and support re transfers and equipment</li> </ul>	<ul style="list-style-type: none"> <li>▪ Maintain maximum independence and mobility with minimal delays</li> <li>▪ Appropriate funding and equipment modification secured</li> <li>▪ Carer and client can transfer and operate safely and comfortably</li> <li>▪ Risk of injury, falls reduced, carer burden lowered</li> </ul>
11.	<b>Carer strain/burden</b> (Carers of people with PD have worse outcomes for anxiety, depression and long-term well-being than other carers)	<ul style="list-style-type: none"> <li>▪ Identify and discuss current issues for carer and avenues of added support</li> <li>▪ Reduce strain on carer by offering &amp; engaging services: <ul style="list-style-type: none"> <li>• respite</li> <li>• hygiene assistance</li> <li>• volunteer support</li> <li>• counselling</li> <li>• carers allowance</li> <li>• financial counselling</li> <li>• education for practical home care issues e.g. managing a syringe driver</li> <li>• transfer and lifting</li> <li>• carer support group</li> </ul> </li> <li>▪ Explore additional or alternative care sources (home care/RAC)</li> <li>▪ ACAS assessment or review if appropriate</li> </ul>	<ul style="list-style-type: none"> <li>▪ Monitor ongoing health and well-being of carers</li> <li>▪ Carers feel well supported and able to maintain their role</li> </ul>

## Parkinson's Disease (PD) Example Care Plan

	Care Issue	Action Plan	Desired Outcome
12.	<p><b>Effective communication</b> (May be impacted by changes to the voluntary muscles of the tongue and face, as well as the facial nerves, altered secretions and fatigue) (Changes in cognition/language may occur with the development of Lewy Body Dementia)</p>	<ul style="list-style-type: none"> <li>▪ Ensure that the current forms of communication are known and documented and conveyed to team</li> <li>▪ Ensure those in contact with the client are taught how to communicate with the person with PD and in their preferred mode</li> <li>▪ Regular assessment and treatment with speech pathologist and neuropsychologist assessment if cognition is affected</li> <li>▪ Ensure glasses and hearing aids fitted &amp; working</li> <li>▪ Work with speech pathologist to introduce alternate communication methods if needed</li> </ul>	<ul style="list-style-type: none"> <li>▪ The client can communicate effectively with treating team without explaining it to new staff</li> <li>▪ Fatigue is reduced</li> <li>▪ The client feels supported, listened to and is able express their personality, values and wishes</li> </ul>
13.	<p><b>Monitor quality of life</b></p>	<ul style="list-style-type: none"> <li>▪ Ongoing assessment of quality of life for client, and primary caregiver</li> <li>▪ Consider therapies that will assist with self-expression and personal meaning such as:                             <ul style="list-style-type: none"> <li>• art</li> <li>• music therapy</li> <li>• counselling</li> <li>• pastoral care</li> <li>• dignity therapy</li> <li>• life stories</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>▪ Optimal symptom control</li> <li>▪ Participation in appropriate therapies and activities</li> <li>▪ Improved quality of life</li> </ul>
<ul style="list-style-type: none"> <li>▪ The recording of data on a care plan will be in accordance with the practices and documentation of each agency.</li> </ul>			