Meeting the Challenges of Parkinson’s Disease (Part 3 of 3)

Resources collated for the WACHS South West Clinical Update Day
May 2013
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All information current at May 2013. No responsibility accepted for currency of information accessed after this date
Resource description

These resources were collated by the WA Health Training Centre in Subacute Care (TRACS WA) for the PD Clinical Update day initiated by Bunbury Hospital Subacute Services held in May 2013. This document is a collation of the presentations delivered.

All information was current at the time of the event.

TRACS WA provided funds from the Subacute Learning Fund to support the day and worked with the South West Subacute service to develop the content.

The input of WA Health staff in the development of these resources is acknowledged within the body of the work.

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Presentation Titles (all parts)

1. Overview of the Day
   Stephanie Daniels, Regional Sub Acute Care Coordinator WA Country Health Service - South West

2. Parkinson’s Disease Overview
   Dr Ramesh Parthasarathy, Geriatrician Bunbury Hospital

3. Medical management: pharmacological therapies in PD and side-effects
   Dr Ramesh Parthasarathy, Geriatrician Bunbury Hospital

4. Medication management and nursing implications
   Marieta Simmons- NCWA Neurological Nurse

5. Consequences of PD and Rehabilitation Strategies (The Kingston Principles)
   Tanya Larsen (OPH Senior Physiotherapist)

6. Managing mobility and activities of daily living: Practical assessment and treatment strategies
   Tanya Larsen (OPH Senior Physiotherapist) and Emily Cheetham (OT, OPH)

7. Falls, Exercise and the Evidence
   Tanya Larsen (OPH Senior Physiotherapist)

8. Non-motor symptoms and management implications: Autonomic symptoms; Sleep; Mood; Cognitive decline/ dementia
   Jo Chadwick (PDAWA Nurse Specialist) and Emily Cheetham (OT, OPH)

9. Preventing malnutrition, weight loss and complications associated with aspiration
   Denise Stapleton and Gillian Penman (Dietitian & Speech Pathologist Fremantle Hospital – Moss St Clinic)

10. Addressing patient and carer support – case management and future care planning
    Beng Lin Tan (Social Work Fremantle Hospital – Moss St Clinic)
The Non Motor Symptoms of Parkinson’s

Jo Chadwick
Parkinson’s Nurse Specialist
Parkinson’s WA
And
Emily Cheetham
Occupational Therapist
Parkinson’s Disease Clinic, Osborne Park Hospital

Jo Chadwick PNS
Summary of presentation

- Overview of non-motor symptoms in PD
  - Key issues including:
    - Orthostasis
    - Constipation
    - Pain
    - Sleep
    - Mood
    - Cognition
  - Prevalence
  - Cause
  - Symptoms
  - Treatment

Jo Chadwick PNS
Collated by TRACS WA
What did we know?

James Parkinson

• Sleep disturbance
• Constipation
• Dysarthria, dysphonia
• Dysphagia
• Sialorrhoea
• Urinary incontinence
• “at the last, constant sleepiness with slight delirium”

Jo Chadwick PNS
Non Motor Symptoms (NMS) of PD

• “the wonder drug” levodopa discovered - motor symptoms improved
  ++ But motor complications & not all motor symptoms responded to
    levodopa - other pathways?
    – Non motor symptoms gained more attention - independent of
dopa systems
    – PD no longer considered a motor disorder but a progressive
      multiorgan disease with many neurological & non motor changes
    – NMS often not recognised as part of PD - mistaken for a separate
      symptom, disease or condition
    – Related to both disease & side effects of PD meds
    – Can occur at any stage of Parkinson’s
  – Variable/unpredictable – every individual is unique
When?

Parkinson’s Disease Timeline

C H Hawkes, Parkinsonism & Related Disorders, Volume 16, Issue 2, February 2010, Pages 79-84

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Braak theory – 6 stage process

Early manifestation of non motor symptoms

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Non Motor Symptoms

- **Sensory**
  Anosmia (inability to smell), Visual deficits, Ageusia (inability to taste), Pain, Paraesthesia

- **Autonomic dysfunction**
  Orthostatic hypotension, GI disturbance, urinary problems, Sexual dysfunction, Sweating

- **Sleep disturbances**
  Excessive daytime somnolence, Insomnia, REM behaviour disorder, Restless leg syndrome, Sleep Apnoea

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Non Motor Symptoms

• **Mood Disorders**
  - Depression, Apathy, Anxiety & Panic Attacks

• **Neuropsychiatric**
  - Hallucinations, Illusions, Delusions, Punding & Impulse control disorder

• **Cognitive Impairment & Dementia**

• **Others**
  - Seborrhoea, Weight loss, Weight gain

Jo Chadwick PNS
Etiology of autonomic dysfunction in PD

Lewy body pathology has been identified in both the central and peripheral autonomic systems. This results in abnormal activation of the parasympathetic & sympathetic systems, producing constipation, delayed gastric emptying, urinary retention, erectile dysfunction, orthostasis & thermo dysregulation.
Causes of Constipation in PD

- Colonic dysmotility + Anorectal dysfunction
  - Combination of disordered contraction & relaxation of muscles of defecation » excessive straining, pain, sense of incomplete evacuation

- Motility decreased - slowed transit time (est. 2x/longer than controls)

- Other factors:
  - Medications (For PD & other)
  - Lack of dietary fibre
  - inadequate fluid intake
  - Lack of exercise
  - Aging; other co-morbidities
Medications and Constipation

- Aluminium or calcium antacids - Mylanta
- Anticholinergic agents:
  - Tricyclic antidepressants – Nortriptyline, dothieprin
  - used for urinary incontinence (Ditropan, Oxybutnin, Tolterodine, Vesicare)
  - Tiotropium used in COPD.
- Antispasmodics – peppermint oil or tablets
- Parkinson’s medication – Benzhexol, Benztropine, Biperiden
- Anti-psychotic medication - clozapine, olanzapine, risperidone, quetiapine
- Iron preparations
- Opioids
- Verapamil

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Treatment of constipation: a stepladder approach

- Increase dietary fibre & fluid
- Increase exercise
- Fibre supplements (psyllium or methylcellulose)
- Stool softeners (docusate)
- Osmotic laxative (lactulose)
- Polyethylene glycol electrolyte-balanced solutions
- “on” “off” periods can influence ano-rectal function » toilet during “on” period
- Stimulants (Bisacodyl-tab or suppositories) (Senna with/without coloxyl, tab or granules)

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Orthostatic Hypotension in PD

- Occurs in 48% - 60% PWP (can be symptom asymptomatic)
- Aetiology multifactorial (Lewy body degeneration in Hypothalmus, brainstem & peripheral nervous system)
- Drop in systolic BP of 20 mmHg after standing or to systolic less than 90mmHg
- Symptoms- Fatigue, visual disturbance, cloudy thinking, neck/shoulder pain, pre-syncope, syncope, falls
Orthostatic Hypotension in PD

Management

- No swift changes of position – stand up slowly
- Eliminate or reduce antihypertensive meds if possible
- Reduce or change Anti-parkinson’s meds
- Increase dietary salt & fluid
- Compression stockings
- Avoid/reduce caffeine and alcohol
- Avoid excessive increase in body temperature (bath, sauna)
- Eat frequent small meals
- Elevate head of bed by 30°- 40°
- Salt retaining steroid (eg. Fludrocortisone)
- Direct acting sympathomimetic (Midodrine)
Sleep Disturbance in Parkinson’s

• Very common 60% - 98% affected
• Can occur at pre clinical stage (Braak’s theory)
• Usually worsens as disease progresses
• Etiology – multifactoral – may be part of disease:
  – The neurodegenerative process – affecting centres that regulate sleep + wakefullness
  – Or /and result of medications & co morbidities
Spectrum of sleep related symptoms in PD

- **Disturbance during day** – excessive daytime sleepiness EDS common in PD (? If cause Dopa-agonist & other meds) or depression or unsatisfactory sleep, ↓ function + boredom

  **Disturbances at night**

  - PD motor symptoms - Akinesa, cramps, tremor
  - Nocturia - ? Cause - PD, prostate, or medication
  - Vivid dreams & hallucinations - ? PD or medication
  - Restless leg syndrome - Irresistible urge to move legs + sensations
  - Periodic limb movement - periodic jerks of lower limbs-repeated awakenings
  - REM sleep behaviour disorder – may precede emergence of motor symptoms -? Lewy body pathology in medulla & Pons

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Insomnia is very common. Try not to lose any sleep over it.
Management of sleep disturbances in PD

Sleep disturbance at night

- Review meds
  - Some prevent sleep: Selegline (amphetamine metabolites), Amantadine, Diuretics
  - Some could promote sleep: For Hallucinations - If dose reduction of PD meds, anticholinergics or other med changes ineffective - Antipsychotics
  - Treat wearing off & motor symptoms with CR meds or ER agonists
- Restless legs - If low ferritin-correct, try dopamine agonist, clonazepam or gabapentin
- REM sleep behaviour disorder – Melatonin, clonazepam+ make environment safe
- Treat depression & anxiety: CBT, Antidepressants
- Sleep apnoea- sleep study, CPAP machine
- Involve the OT

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Strategies to assist with sleep

• Sleep diary-identify patterns, habits etc

• Sleep hygiene education
  – maintain Circadian rhythm: bright light day – darkness@ night
  – bedroom only for sleep - remove TV

• Bed mobility retraining

• Consider use of overnight mobility strategies
  urinals, bedside commode etc

Emily Cheetham OT

Jo Chadwick PNS

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Fatigue in Parkinson’s

Features
- Physical fatigue
  - Bradykinesia, tremor, dyskinesia, hypokinesia, akinesia etc
- Mental fatigue
  - Bradyphrenia, cognitive movement strategies require constant attention
- Amotivation and social withdrawal

Management Strategies
- Assess using activity record or fatigue scales
- Energy conservation education
  - Prioritising and delegation
  - Planning
  - Pacing
  - Posture and task modification
- Relaxation
- Exercise

Emily Cheetham, OT  Jo Chadwick PNS
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Pain in Parkinson’s

• Experienced by 70% -80% of people with PD
• Most unrecognised & undertreated NMS
• Mentioned by James P in original essay X 21
• Pain can be categorized into
  – Peripheral mechanical pain
  – Central neurological pain
• PWP have less ability to modulate the heightened sense of pain

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# Pain

<table>
<thead>
<tr>
<th>TYPE</th>
<th>PRESENTATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Musculoskeletal</td>
<td>Aching muscles and joints</td>
</tr>
<tr>
<td></td>
<td>Arthritis blamed</td>
</tr>
<tr>
<td>Dystonic</td>
<td>Extremity involvement, painful spasms</td>
</tr>
<tr>
<td></td>
<td>Typically in off state</td>
</tr>
<tr>
<td>Akathisia</td>
<td>Sense of internal restlessness</td>
</tr>
<tr>
<td></td>
<td>Usually involves legs</td>
</tr>
<tr>
<td></td>
<td>Typically in off state</td>
</tr>
<tr>
<td>Neuropathic (radicular)</td>
<td>Shooting or tingling pain (pinch nerve blamed Limited to dermatome</td>
</tr>
<tr>
<td></td>
<td>Dyskinesia may trigger</td>
</tr>
<tr>
<td>Neuropathic (central)</td>
<td>Bizarre quality</td>
</tr>
<tr>
<td></td>
<td>Difficult to localize</td>
</tr>
<tr>
<td></td>
<td>Occurs in off state</td>
</tr>
</tbody>
</table>

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Pain Management in PD

• Difficult to treat
• Depends on type of pain
• PD medication management (e.g. on-off diary)
• Dopaminergic therapy for RLS
• Treat depression as can augment the subjective feeling of pain
• Gabapentin for neuropathic types of pain
• Atypical Neuroleptics for oral/genital pain Botulinum toxin for dystonia
• Referrals
  – Physical therapy
  – Occupational therapy
  – Pain management
Depression in PD

• Depression is the most common non motor symptom in PD
• Major depression can predate onset of motor symptoms & diagnosis of PD by years
• Not always a reaction to diagnosis, disability, negative effect on job, economic security & reduced QOL
• More common in young onset group
• Can impact motor & non motor symptoms
• Associated with increased caregiver burden & depression
• Severity not necessarily related to degree of disability
Aetiology of depression in PD

• Psychological hypothesis: logical reaction when suffering from a chronic disabling disease

• Neurobiological Hypothesis:
  Loss of brainstem monoaminergic neurones (dopaminergic, noradrenergic, serotonergic & cholinergic) with degeneration of their respective cortical & subcortical projections (basal ganglia, midbrain, limbic)

• A mix or combination of psychological & biological factors

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Depression in PD

Symptoms of depression in PD vary slightly
- In PD – less guilt & self reproach
- More irritability, sadness & concern with health
- More anxiety & sleep disturbance.
- Less energy & motivation. More concentration difficulties.
- Less suicidal ideation
- Mood fluctuations can accompany motor fluctuations of “on/off” states

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Symptom’s common to both Parkinson’s & Depression

• Slowed movement
• Masked facies
• Bradyphrenia
• Stooped posture
• Voice changes
• Deterioration in health

• Sexual dysfunction
• Insomnia
• Hypersomnia
• Appetite changes
• Restlessness
• Reduced concentration

Hence can be difficult to diagnose
Diagnosis of depression in PD

Use standardized depression scales such as

- Beck Depression Inventory
- Geriatric depression scale

- Include as part of initial assessment & at regular follow up’s
- Progressive disease – advancing disease severity & functional deterioration can trigger relapses
Treatment

• Parkinson’s Nurse / Nurse Specialist
  Explaining - depression a common & intrinsic part of PD can help person to accept help & treatment
• Psychological - Cognitive behavioural therapy
• Interpersonal therapy, Self help strategies
• Medication - Optimise dopaminergic therapy first Tricyclics, SSRI’s, SNRI (Venlafaxine)
• Combination of psychological & medication best option
• ECT
• Role of exercise & remaining active
• Healthy diet
• Supportive family & friends
• Beyond Blue + fact sheet

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Features

- 40% of PWP meet DSMIV criteria for anxiety and many more experience anxiety traits
- Dopamine withdrawal “on”/”off” periods
  - Panic attacks
  - Motor fluctuations
  Eg. “What if I freeze when crossing the road?”

Strategies

- Relaxation training
- Planning for potentially stressful events e.g. neurologist appointment
- Mindfulness
- Education and reassurance
- PD Anxiety specific Ax tool being developed by Dr Albert Leetjens, Masstricht, Netherlands
- Consider referral to Clinical Psychologist through PDC or to GP for Chronic Disease Management Plan

Emily Cheetham, OT  Jo Chadwick PNS

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Cognitive changes in PD

“Involuntary tremolous motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forwards, and to pass from a walking to a running pace; the senses and intellect being uninjured”

James Parkinson in 1817
Cognitive changes in Parkinson’s

• Charcot 1877 stated that “at a given point, the mind becomes clouded & the memory is lost”

• We now realise that changes in cognitive function often occur very early (first 1-2 years) & form an integral part of the clinical presentation
Aetiology of cognitive dysfunction

- Associated with diffuse subcortical & cortical Lewy body pathology.
- Degeneration of neural circuits connecting the Basal ganglia and cortical regions including the pre frontal cortex
- Also several neurotransmitter deficiencies (Cholinergic, dopaminergic, noradrenergic & serotonergic) impairing memory, causing executive dysfunction, impaired attention and depressed mood
Symptoms of cognitive dysfunction

Symptoms vary –
One or more cognitive domains can be involved

Cognitive domains

- Memory & learning
- Attention
- Working memory
- Executive function
- Language
- Visuo-spatial & non verbal skills
- Speed of information processing

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PwP and Attention: Features

• Attention fluctuates due to fatigue and as the brain changes
  • Focussed: Generally unaffected.
  • Sustained and Selective: Easily distracted e.g. by noise, looking out a window
  • Shifting/alternating: Difficulty changing from one task or conversation topic to another. e.g. Losing train of thought when conversation interrupted.
  • Divided: Difficulty with dual tasking and complex tasks which require a high level of attention e.g. driving
  • Speed of processing: Bradyphrenia (slowness of thought processing)
PwP and Attention: Strategies

• Make sure you have the PwP attention before giving new information e.g. call their name
• Eye contact
• Encourage the PwP to repeat information back to confirm message has been received e.g. “So I’m meeting you outside The Birdcage Coffee Lounge at 10:30 on Tuesday?”
• Reduce distractions (visual clutter, noise etc)
• Give one piece of information at a time
• Use of gestures
Cognition: Short Term Memory

- **Features**
  - Difficulty with memory retrieval due to organisational problems.
  - e.g. the information is misfiled
  - PwP describe “on the tip of my tongue” frustration
  - New learning possible but will need repetition & information must be related, not random

- **Internal Strategies**
  - Chunking of information
  - Associations
  - Repetition
  - Routine

- **External Cues**
  - Calendars/diaries
  - Whiteboard in prominent place
  - Alarms/timers
  - Notepad
  - Cue card
  - i.e. back of front door
Cognition: Planning

• **Features**
  – Impacted by bradyphrenia
  – Appear disorganised e.g. take longer than would normally be expected, to get ready to go out.
  – Difficulty moving through a task from beginning to end e.g. cleaning out a room can be viewed as somewhat overwhelming

• **Strategies**
  – Cognitive checklist STOP-PLAN-DO-CHECK
  – Use cue cards
  – Consider “on”/”off” times
  – Reduce distractions
  – Allow time; don’t rush
  – Structured approach

Emily Cheetham, OT    Jo Chadwick PNS
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Summary

• More than motor symptoms
• NMS impact substantially on a person’s QOL
• NMS contribute significantly to the economic impact of PD on society. Key cost drivers are hospitalisation & institutionalisation - often occur in PD (for reasons such as hallucinations, falls, dementia)
• Delayed detection of NMS increases disability, causes poor QOL & overall increase in cost of care
• Medication management makes-or-breaks patient comfort and level of care required
• Greater understanding of & earlier recognition by health professionals is essential
• Team approach best: strategies can significantly improve outcomes & quality of life

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Jo Chadwick PNS
Time for afternoon tea
Spot the falls risk!
TRACS Parkinson’s Disease Study Day

Speech Pathology and Dietetics in Parkinson’s Disease
May 2013

Gillian Penman, Snr Speech Pathologist
Denise Stapleton, Snr Dietitan
Speech Pathology and Parkinson’s Disease

Main areas of assessment and ongoing management:

• Voice
• Speech and Communication
• Oral and Pharyngeal Dysphagia (swallowing)
• Non-medical management of Saliva
• From early onset to palliative support
Voice – main features

- Decreased loudness (reduced vocal volume)
- Hoarseness (husky/hoarse voice quality)
- Breathy (poor respiratory coordination to support phonation)
- Talking on residual air (running out of air while still talking)
Speech & Language - main features:

- Decreased or increased rate of speech
- Impaired articulation – lack of clarity (lips and/or tongue not moving quickly to make speech sounds)
- Difficulty initiating speech
- Losing the thread of the conversational topic, word finding difficulties
Saliva and Parkinson’s Disease

- Dry mouth (xerostomia) – may be a side effect of various medications
- Dribbling/drooling (sialorrhoea) – reduced frequency of swallows, reduced awareness of saliva building up in the oral cavity
- Mixed xerostomia and sialorrhoea
Dysphagia in Parkinson’s Disease

Impairment of motility in both the oral and pharyngeal stages of the swallow e.g.

• difficulty forming the bolus
• difficulty effectively transferring the bolus from the front of the mouth to the back of the mouth
• difficulty initiating the swallow
• impaired movement of the bolus through the pharynx and oesophagus
Common dysphagic changes in PD: Oral phase

- Impaired mastication and lingual movements
- Increased number of swallows per bolus
- Tongue pumping
- Increased oral transition duration
- Residue on tongue and anterior and lateral sulci
Common dysphagic changes in PD: Pharyngeal phase

- Prolonged trigger of the pharyngeal swallow initiation
- Prolonged laryngeal movement
- Decreased laryngeal control pressure
- Vallecular and pyriform sinus residue
Oro-pharyngeal dysphagia and neuropathology in PD

Dysphagic changes in Parkinson’s Disease are attributed to:

• Reduced movement (hypokinesia)
• Slowness of movement (bradykinesia)
• In the case of tongue pumping – hesitation of movement (akinesia)
Progressive malnutrition in PD due to
Increased energy expenditure: tremor & dyskinesia
Uncontrolled & unpredictable rigidity & tremor
Constipation -limits appetite
Depression
Anorexia
Medication side effects
  eg. nausea, reduced smell, dry mouth & anorexia
Dysphagia
PD associated dementia
Inability to feed self/prepare meals etc due to involuntary movements
Subjective Global Assessment (SGA)

Team awareness of components of SGA enhances likelihood of detection and prevention of malnutrition

**Rating** weight change: 6/12 & 2/52 (note oedema & ascites)

dietary intake: adequacy, texture & change

**Frequency & duration** of nausea, vomiting, diarrhoea, anorexia, taste changes, constipation

**Nutrition related functional impairment**

**Physical rating** of subcutaneous fat & muscle loss
Subjective Global Assessment

• DVD
TABLE ACTIVITIES

• In groups of 5/6:

• Complete the activities on each table
• Move to the next table when you hear the signal
• You will have 3 minutes to complete each activity
• HAVE FUN!
Progressive malnutrition & weight loss

35-40% pts require intensive support nourishing meals +/- nutritional supplements
IP& OP: refer to dietitian for high protein & energy meals, snacks & fluids

Early satiety (delayed GI emptying):
Provide small frequent meals & nutritious snacks

Texture modification:
Increase food appeal & appearance

Optimise oral intake during “on times”
Voice management in Parkinson’s Disease

- Individual or group sessions
- General voice or intensive voice sessions
- LSVT or Lee Silverman Voice Treatment (LSVT) – 4 sessions 4x per week for 4 weeks. Gold standard Evidence Based Practice Intervention
- Deep breathing
- Coordination of respiration with phonation
- General voice care
Language, Speech or general dysarthria management in Parkinson’s Disease

- Slowing down the rate of speech, voluntarily or using pacing boards
- Attending ‘Dysarthria Gym’ – PD and non-PD multi-disciplinary group
- Language groups for the person with PD (with or without dementia) and carer
- Individual sessions
Dysphagia management – decisions made following clinical, and/or videofluoroscopy, assessment

- Diet modification
- Fluid thickness modification
- Posture and head position
- Frequency of meals and timing
- Medications with pureed apple rather than water
- Modified utensils e.g. Cut out cups – head backward tilting minimised
Saliva management

• Xerostomia: dry mouth products such as mouth gel, toothpaste, mouth wash; sip water; etc

• Sialorrhoea: Non-medical - sip water; visual/auditory cues to remind about swallowing; chew gum; etc. Medical Management - atropine drops (need to be cognisant of side effects); neurobotulinum toxin injections
# Speech Pathology Model of Care in Parkinson’s disease

<table>
<thead>
<tr>
<th>PD Stage</th>
<th>Early</th>
<th>Middle</th>
<th>Advanced</th>
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<tbody>
<tr>
<td>Therapy Focus</td>
<td>Education</td>
<td>Education reinforced</td>
<td>Maintenance/Compensation</td>
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<tr>
<td></td>
<td>Rehabilitation</td>
<td>Rehabilitation/Maintenance/Compensation</td>
<td>Carers’ education and training</td>
</tr>
<tr>
<td></td>
<td>Empowerment</td>
<td>Empowerment reinforced</td>
<td></td>
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</tbody>
</table>

## Dysarthria therapy provision
- Individual voice/speech therapy
- Voice/speech home program
- Individual maintenance therapy
- Maintenance home program
- PD voice group
- PD choir

- PD voice group → PD maintenance group
- Carers’ workshops
- AAC

## Dysphagia management
- Dysphagia, xerostomia & saliorhea education
- Diet and fluid modifications

## Types of service delivery
- Initial assessments
- Annual reviews
- Dysarthria reviews
- Dysphagia reviews
- 6-month reviews → Home visits

Delivering a Healthy WA

Collated by TRACS WA
Meeting the Challenges of Parkinson’s Disease

Social Work, Case Management and Future Planning

May 2013

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Case management defined:

“a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s holistic needs through communication and available resources to promote quality cost-effective outcomes.”

Case Management Society of Australia (CMSA)
Case Management Principles

- Individualised service delivery
- Comprehensive assessment
- Develop service or care plan
- Collaboration with client and carers that reflects their choices and preferences
Social Worker’s Functions

- Conduct comprehensive assessment
- ACAT assessor
- Support, counselling, education
- Link to community care sector and other health professionals
- SW Report filed and copies to GP, PNS, Neurologist, other hospitals / ACATs
Comprehensive Assessment

- Medical history – medical records, discharge summaries, team’s reports
- Local ACATs re previous assessments
- Social history, support networks
- Community supports
- Activities of daily living + overnight assistance
- Medications and management
- Mental state, behaviour, mood – MMSE, GDS
- Issues/risks identified
- Recommendations and Interventions
Identify Issues/Risks

- Changes or decline in function
- Decreased intake, unplanned weight loss
- Falls and near falls/stumbles
- Incontinence and inadequate management
- Constipation
- Poor compliance or management of medications
- Cognition, behaviour, mood
- Carer stress
- Inadequate support services or home aids
- Financial, legal, accommodation
Interventions

- Recommendations and Care planning
- Refer to & coordinate services
- Education and information
  - PD, medication timing/management, services and respite options
  - Importance and benefits of maintaining carer’s well-being
- Advocacy, support counselling
Interventions (cont.)

- Refer to team or other professionals
- Complete ACCR for residential, respite care and care packages
- Assistance with/advice on financial entitlements or grants – Centrelink benefits, ILC Disability Equipment Grant, Thermoregulatory Dysfunction Energy Subsidy Scheme

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Future Planning

- Residential respite approvals
- Crisis and emergency respite
- Future services and respite options
- EPA – Enduring Power of Attorney
- EPG – Enduring Power of Guardianship
- AHD – Advanced Health Directive
Focus

- Maximise functional independence and quality of life
- Maintain carers’ health and well-being as they are integral in the care of PWP
- Education of PWP and carers regarding self-management strategies – exercise, medication
Focus (cont)

- Collaborative approach – with clients/carers, health professionals and service providers
- Integrated care – with PNS, interdisciplinary care at DTUs, Specialist Clinics
- Continuum of care – referrals to specialist services, PNS, DTUs and community based exercise programs
Case Presentation

- 76 yo man cared for at home by his wife
- Diagnoses:
  - Parkinson’s Disease – Dx 1992
    - drooling, some functional decline
  - Mild memory loss
  - ?IBS – chronic loose stools
  - infrequent faecal incontinence
  - Sacral pressure sore – dressings
Social Situation

- Second marriage for both
- Wife 65 yo, has Heart Disease
- Wife drives, assists with ADLs, home duties
- Client has 1 son, locally – has family & work, min. support
- Wife has supportive daughter in country
- Current HLC approval – R, RC, EACH
ADLs

- Independent mobility/transfers in day and with showering
- Assistance drying, dressing, pulling up pads after toileting, transfer into bed
- Occasional feeding assistance due to tremor
- Overnight assistance up to several x a night – TV, transfer into bed
Support Services

- EACH Package – pc assistance 7/7
  IHRC 1.5 hours x 3/7, woundcare
- Day Centre 1/7
- Parkinsons Nurse Specialist r/v
- Podiatrist
- Crisis Care in the past
- Parkinson’s Services SMHS
Situation

- Referral from CCT PT
- Wife presented to ED with stress-related chest pains
- Urgent respite requested
- Previous booked residential respite brought forward
Issues

- Carer stress impacting on health
- Long term poor sleep pattern – assistance to transfer back into bed –
- Loose bowel actions at night
- Assistance to pull up pads after toileting
- Hx Strained relationship – son and carer
- Conflict between both families – anger; blame

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Issues (cont.)

- Client unhappy in respite – uncooperative, withdrew from activities
- Son querying re client’s wife entering residential care with client
- EACH package maximised
Actions

- Diffused situation
- Explored options – home vs ACF
- Plan: Trial at home with back-up plan; Son to stay and assist overnight; chart assistance
- Arranged and facilitated 2x meetings:
  i. with client, son and wife, post respite; explained aim and provided chart
  ii. Reviewed with son, wife, PNS, EACH coordinator
Actions (cont)

- Reviewed care plan with EACH coord.
- Referred wife to HACC for DA and IHRC for client
- Support counselling and advocacy for wife
- Education – Parkinson’s Disease; importance of maintaining carer’s health and reducing risk of carer stress
Actions (cont)

- Rebooked Medical review
- Referred to Dietitian
- Referred to SP re drooling
- Referred to OT re bed transfers & toileting/pads
- Centrelink Illness separated rate and Carer Respite Centre
Outcome

- Client remained at home with extra services
- Overnight assistance reduced to 1x/night
- Lactose-free diet – reduced incidences of loose bowels
- Atropine drops – dribbling improved
- Independent toileting with Strategy of pulling pad down to thighs/knees

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Outcome (cont)

- Son has greater understanding of PD, extent of client’s needs and empathy for carer
- Son more supportive
- Increased services
- Carer received HACC DA and IHRC
- Carer expressed reduced stress
- Received Illness-Separated Rate from Centrelink & fee assistance from CRC

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Follow-Up

Prior to 2\textsuperscript{nd} respite – met with client and family, PNS and EACH coordinator

On follow up:
- more settled, cooperative and engaged in activities
- carer happier

Regular respite care recommended

Prior to 3\textsuperscript{rd} respite – carer confident in discussing with spouse herself

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Sincerest thanks to all of our presenters

Please fill in your evaluation forms

Don’t forget your PD resource packs!

Delivering a Healthy WA