The Winston Churchill Memorial Trust of Australia

Report By:

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2000 Churchill Fellow

The Vincent Fairfax Churchill Fellowship to study overseas

*Best Practice in the Community Based Management of Parkinson’s Disease*

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“It is no use saying we are doing our best. We have to succeed in doing what is necessary.”

- Sir Winston Churchill
**Introduction**

The purpose of undertaking the Vincent Fairfax Churchill Fellowship was to investigate best practice models of community based management programs for Parkinson’s Disease, in Sweden, the United Kingdom and New Zealand.

Parkinson’s Disease is a chronic, progressive neurological condition. With the ageing of our population, so the incidence of chronic disease increases. It is of critical importance that there is forward planning to put in place strategies and services that will effectively address the needs of this population to maintain their optimum quality of life.

This study was undertaken in response to an identified need in South Australia, where services for Parkinson’s have been generally inadequate, poorly coordinated and often unknown by the people who require them the most and their medical practitioners.

The information presented in this report can be used to stimulate interest, and to develop and implement innovative and effective services and therapy programs for people with Parkinson’s and their carers, in Australia.
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- Ms Caroline Noble PDNS (Peterborough)
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- Mr Gary Hattie (YAPP&RS)
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- Mr Wayne Maher BPhED (Multiple Sclerosis and Parkinson’s Society of Canterbury).
Executive Summary


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Project Description
The examination of innovative community based services, which facilitate the effective long-term management of Parkinson’s, in Sweden, the United Kingdom and New Zealand, and to recommend strategies, which could be utilised in Australia.

Key Strategies - Sweden, the United Kingdom and New Zealand
- The critical role of education – People with PD, carers, health professionals, carer workers.
- Benefits of PD Clinics. – Geriatrician led
- Interdisciplinary teams and evidenced based practice.
- Holistic, coordinated, seamless care.
- Parkinson’s Disease Nurse Specialists
- Self-management skills. – Expert Patients Programs.
- Quality of life as the outcome measure.
- The recognition of the role of exercise and complementary therapies.
- Addressing the special needs of young people with PD., carers and minority ethnic groups.
- PD support groups - advocacy and support.

Recommendations
To successfully address the needs of people with Parkinson’s and their carers it is necessary to adopt a positive and proactive approach to the continuum care that is required to manage this chronic degenerative disease. I believe we can learn a great deal from the models in place overseas, drawing on the many common shared ideas and innovative practices, to provide the direction for change and to use as a basis for program development in Australia.

The current community based therapy services are ideally placed to provide ongoing Parkinson’s therapy-focussed management programs. To facilitate this, we need:
- Hospital based Parkinson’s Disease clinics to manage the medical complexities of Parkinson’s and to efficiently refer people onto community based services.
- Interdisciplinary health care teams using joint goal planning to facilitate functional outcomes.
- Specific Parkinson’s education for all the relevant health professionals and care workers.
- Research to develop innovative best practice management programs – both traditional and complimentary therapies.
- Guidelines for standards of practice and evaluation protocols to maintain quality.
- An ethos, which enables and empowers patients to have an active, educated role in the management of their disease.

Dissemination and Implementation.
It is vital to raise community awareness that Parkinson’s can be managed positively and effectively.
The Fellowship recommendations will be distributed and/or presentations made to the National and State Parkinson’s Associations, relevant Hospital Neurological and Rehabilitation Units, Professional Special Interest Groups, residential Aged Care Organisations, community Aged Care Therapy Services, interested Medical Practitioner groups, Consumer groups, Community Service Clubs, local media - radio and newspaper. To date most these areas have been addressed.
The Parkinson’s Associations and health professionals have a major role to play in advocating, for a concerted national approach to educate health workers and provide specific Parkinson’s management services.
Implementation is most effectively achieved through education at all levels and by persistent lobbying.
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“The onset of Parkinson’s starts a journey into the unknown – a journey which is uncharted, unwanted and which can be very lonely”

- Australian Parkinson’s Association.
Investigating Best Practice in the Community Based management of Parkinson’s Disease

World wide chronic illness is increasingly recognised as a major cause of expenditure within health care systems. This comes at a time of growth in the elderly population and an increasing focus on disability and handicap negatively impacting on peoples’ ability to have an active, participatory life.

Parkinson’s disease is a chronic, progressive, degenerative, neurological condition with no cure. It is relatively common affecting 1% of the population over the age of sixty, rising to 2% over the age of seventy, with statistics showing a higher frequency of diagnosis.

Parkinson’s is a devastating disease, “a whole range of personal and circumstantial features interact with the progress of the disease to produce a highly individualised and changing pathway”. Parkinson’s is unpredictable in the long term and very variable in the short term, and it requires specialist care that can cross the organisational boundaries of health and social care services. (Parkinson’s disease: Studies in Psychological and Social Care 1999.)

The impact of Parkinson’s is costly to individuals, families, communities, health and social services.

In 1997 Parkinson’s Disease was made a public health priority by the World Health Organisation and it has been predicted that demand for comprehensive Parkinson’s services will increase in the next few decades. (Moving and Shaping the Future 1999).

Although medical treatment has greatly advanced it is still only palliative, aimed at alleviating the motor and to some extent the cognitive and emotional symptoms. Prolonged pharmacological treatment itself creates complications that further compound the extent of the disability and handicap experienced by people with Parkinson’s. Interestingly, The Global Parkinson’s Disease Survey (1999) commissioned by the Parkinson’s Disease Society in the UK found that rather than being predominantly influenced by disease severity and medication issues, quality of life was impacted more by depression which frequently, was not recognised by either the patient or by their Doctor.

Parkinson’s is a very complex condition and it presents a multiplicity of issues, all of which consequently impact on the lives of any informal carers whose own health and well being needs are often under recognised.

It is unfortunate then that often services for PD are unstructured and uncoordinated with the real possibility of those with PD and their carers being under-serviced or neglected in relation to their ongoing and increasingly complex needs. There is frequently too, a lack of knowledge about Parkinson’s and its treatment among all levels of health workers.

The report, Moving and Shaping the Future (MacMahon, Thomas, Henry 1999) documents a plan for commissioning improved services for PD with in the UK health service. Even though the Australian
health service is different, much of information in this document is relevant here. Moving and Shaping the Future suggests that the systems which show the greatest promise of success integrate:

- Self management
- Guideline based treatment plans
- Nurse case management
- More intensive follow up
- Improvement in Doctors’ skills
- More effective use of non-physician providers

Pathways – A Model of Care (Primary Care Task Force1999) divides the progression of PD into four stages with particular entry criteria through the different stages. Within each stage, are outlined the treatment goals and range of services necessary to achieve the relevant outcomes. The stages range through Diagnosis, Maintenance, and Complex and finally Palliative, with the overall aim of intervention being health gain, health maintenance and finally comfort.

Although this paradigm was designed for primary care general practitioners, as a guide to the management of PD, it is invaluable for all health professionals. If used as a basis for treatment this model provides a proactive paradigm for the long-term management of PD, giving health professionals directions towards optimising independence and quality of life throughout the disease progression. The role of intervention is to obtain a clear picture of patients’ needs and to examine a range of alternatives by which those needs can be met.

Moving and Shaping the Future recognises that input from the health professional team will be required intermittently, and at irregular intervals over the duration of the disease process. To facilitate care management, the report recommends an approach aimed at:

- Early detection and intervention to manage disabilities.
- Easy access to coordinated medical, allied health and social services.
- Team members with a particular interest in PD.
- Protocols in place to maintain up-to-date team education.
- Evaluation of treatment programs, recommending the measurement of quality of life rather than use measures of disease severity only.

Quality of Life is being recognised as the primary concern of any therapeutic intervention and by increasing “personal control and teaching people with Parkinson’s how to improve their quality of life patient satisfaction with the service received” (Moving and Shaping the Future) is raised.

Centres in Sweden, The United Kingdom and New Zealand have many areas of common concern and focus and all are endeavouring to improve the services they provide through focussing on research and the evaluation of innovative programs with the outcome being to optimise quality of life.
1. Lund, Sweden
Lund is a University town in Southern Sweden. The Lund Faculty of Medicine has access to the University Hospital, the Rehabcentrum and Kompassen Rehabilitation Units and the Wallenberg Neuroscience Research Centre.

The Swedish rehabilitation model is based on:

- Developing a collaborative therapeutic relationship with the patient.
- Therapist’s involvement in the continuum of care.
- Research to support theory and practice.
- Patient identified goals driving interventions.
- Enabling patients to participate in goal directed functional activities by modifying physical and social environments.
- Assisting patients through education and training in adaptive and compensatory strategies to enhance their independence.
- Enabling success, which in turn enhances personal satisfaction and improved quality of life.
- Recognition of the role of family members in the rehabilitation process.
- Focussing assessment and evaluation on function and restoration of self-esteem and quality of life.

1.1 Lund University Hospital

The Department of Clinical Neuroscience

While medical and surgical treatment cannot solve all the problems associated with Parkinson’s, pharmacological therapy is still regarded as the basis of modern treatment but only as one part of the total management. A multi-disciplinary team and individualised treatment provides optimal results when used in conjunction with medical management.

The Lund University Hospital program is endeavouring to improve the overall management of Parkinson’s. This new program includes:

- An outpatient clinic
- An inpatient clinic

These clinics are linked to

- The research unit
- And the clinical research department.
The Out Patient Clinic provides a multidisciplinary clinic and is involved with drug challenges, clinical observations, drug adjustments, diagnostic evaluations, phone counselling, and clinical research. It also has available a botox/dystonia clinic.

The Inpatient Clinic is involved in clinical observation, apomorphine introduction, intra-duodenal L-dopa, drug adjustment, diagnostic evaluations, clinical transplantations, emergency cases and functional neurosurgery.

Patients who require immediate ongoing intervention but do not need to be in a nursing ward may stay in the Patient Hotel where nurses are available twenty-four hours a day for help and advice.

The Lund University Hospital and Scandinavian Patient Hotels jointly run the Patient Hotel, which is located in the hospital grounds. Admittance is by a doctor’s recommendation.

The Research Unit situated, in the Wallenberg Neuroscience Centre, works in the area of developing restorative and protective treatments, autonomic dysfunction, differential diagnosis, clinical assessment, impact of the disease and clinical trials. This unit works in conjunction with the University Hospital in Malmo and Lund.

In the Clinical Research Department attention is given to managing motor fluctuations and the use of on/off diaries, the development and use of clinical rating scales, assessment of the functioning of motor and cognitive skills with and without L-dopa, self assessment tools and patient perceived health, function, quality of life, distress and life satisfaction. All of which are relevant to optimising quality of life in the face of the complexities caused by the advancing disease and are of use to allied health clinicians in improving practice.

Some of the papers published from this unit include:

- **Clinical Rating of Dyskinesias in Parkinson’s Disease: Use and reliability of a New Rating Scale.**
  Peter Hagell RN,BScN and Dr.Hakan Widner, MD, PhD. This paper outlines a more definitive scale for measuring the impact of Dyskinesia and Dystonia in later stage PD on quality of life.(QoL) There is no established treatment available for dyskinesia but reports are available on the positive effects of neurosurgical intervention and intra-striatal grafting of embryonic mesencephalic tissue. To evaluate any interventions a reliable and relevant assessment tool is required. This type of assessment tool would also provide information to treating therapists. The aspects of Dyskinesias important to QoL are the daily duration, the influence on daily activities and the amount of dyskinesia induced by a particular dose of anti-Parkinson’s medication. Information in these areas would aid in the planning of intervention to assist patients in managing their personal and instrumental activities of daily living (PADL and IADL) more successfully.

- **Health – related Quality of Life following Bilateral Intra-striatal Transplantation in Parkinson’s Disease-** Peter Hagell et al.

- **Neurosurgery for Parkinson’s Disease: The Role of the Specialized Nurse-Peter Hagell Anna Torquist,**
Restorative Neurology in Movement Disorders-Peter Hagell.
Functional Integration of Neural Grafts in Parkinson’s Disease-Roger Barker & Stephen Dunnett,
Cell Replacement Therapies for Central Nervous System Disorders.- Anders Bjorklund & Ollie Lindvall.
Dopamine Release from the Nigral Transplants Visualised in vivo in a Parkinson’s Patient.-Paola Piccini et al.
Apomorphine in the Treatment of Parkinson’s Disease Peter Hagell & Per Odin which suggests that apomorphine be given a wider application in the treatment of PD and that it should be tried before more invasive interventions are considered.

Inpatient and Outpatient Clinics:
Clinic assessment includes a medical history – physical, mental and social – Parkinson’s history, and a review of patients’ on/off diaries, medication review including apomorphine treatment, blood pressure and weight checks and any laboratory screens that may be required.

The patient and family are the central focus of the rehabilitation team, which includes physiotherapy, occupational therapy, PD nurse, neurologist, social worker, speech pathologist and dietician.

The role of occupational therapy, in the outpatient and inpatients clinics, is to assess and implement an intervention program in conjunction with the medical treatment, which may include medication adjustment and neurosurgery (both stimulation and foetal cell implant) The assessment tools used include:

- The Canadian Occupational Performance Measure (COPM) This enables the patient to define areas of importance in which they are experiencing difficulty, providing the basis for goal planning.
- The Cognistat (The Neurobehavioral Cognitive Status Examination - The Northern California Neurobehavioral Group, Inc 1995)
- The Sollerman Hand function Test (Christer Sollerman) , a Swedish tool assessing 20 types of functional grip.
- The Assessment of Motor and Process Skills (AMPS).

The procedure is to initially use the COPM and follow up with the AMPS to verify the practicality of the chosen goals. This concept is outlined in the paper Uniting Practice and Theory in an Occupational Framework. 1998 Eleanor Slagle Lecture. Ann G. Fisher

Patients are then referred for ongoing rehabilitation to the Rehabcentrum or to Kompassen, both of which are inpatient rehabilitation facilities or to the community based Occupational therapists. A discharge report outlining the ongoing treatment requirements is sent to the community OT’s who in
Interventions are planned in interdisciplinary team meetings and the team has access to other specialties as required. The team also assesses pre and post surgical intervention and medication regime challenges.

In addition to clinical services the unit also provides:
- Information
- Phone counselling
- Post rehabilitation follow up
- A link between patients, relatives and the health care system
- A “Parkinson’s School” - an education program for patients and relatives
- An interactive CD ROM and accompanying booklet, which is used as a teaching aid for patients and carers.
- A primary health care education program for health workers and residential care staff

The new PD Clinic system provides:
- Longer appointment times,
- Contact with a range of health professionals
- Easy access to the team as required.

An evaluation of the program, a year post introduction, canvassed the opinions of the initial fifty-eight patients, who were rated clinically in the moderate to severely affected range
- On the longer time of appointments, compared to regular out patient schedules, 94% reported this to be either good or very good.
- On having contact with a range of health professionals at the clinic 96% rated this as either good or very good.
- On access to the clinic team over 80% preferred ongoing contact rather than once only contact.

The evaluation found that the multidisciplinary approach of the new clinic was favoured and that the increased time spent at the clinic was compensated for by an overall positively perceived outcome and the preferred option of easy access to the team.

1.2 Orup – Rehabcentrum

Rehabcentrum combines with the Lund University Hospital to be Southern Sweden’s most advanced rehabilitation unit. It has purpose designed treatment areas with a comprehensive range of equipment both specialised to particular disciplines and everyday living use eg gym equipment, computer
technology, working patient kitchens, and “allotment” type gardens etc. The local community also has use of the gym and hydrotherapy pool.

The unit specialises in neurological conditions, pain and physical medicine. Patients are predominantly under 65 years of age. Rehabcentrum collaborates with other medical institutions and the department continues to further research and development.

The specialist team, with a high staff/patient ratio, represents medical, psychological, physical and occupational therapies. The unit has an ongoing continuing staff education ethos to maintain and improve treatment standards.

The program is hospital based with patients admitted or staying in the Patient Hotel, which is situated on the campus. Length of stay in the program varies from weeks to months.

The patients’ disability is not treated in isolation but as part of an holistic picture, and progress is closely monitored from the earliest contact to follow up after discharge. Discharge information is provided to the relevant community services.

Relatives are considered to be an important part of rehabilitation, adding extra knowledge about the patient, which can enhance the treatment process.

The occupational therapist and physiotherapist assess all new referrals for acceptance to the program after the Doctor has approved the initial referral. Acceptance is related to the desired goals as defined by the patient.

Assessment includes physical, intellectual and communication functions. The team works together to help the patient define and achieve realistic goals, using an interdisciplinary checklist and goal plan. This process includes the patients’ perspective of their actual abilities and possibilities for the future.

Patients are asked to identify possible issues that would aid or hinder goal achievement and these are noted on the goal and treatment plan. The health team also adds their assessment of possible limitations to goal achievement. Sub-goals are listed within time frames accompanied by their treatment plans and the responsible therapists. Treatment is goal orientated and includes care planning and team meetings with patients and relatives.

Personal goals are made in the following areas, which reflect the initial assessment:

- Eating/drinking
- Personal hygiene
- Transfers
- Communication
Interpersonal relationships
- Instrumental activities of daily living
- Work/studies
- Leisure
- Other special individual goals.

The team has a broad network of contacts with community services and on discharge, continuing care plans are sent to the relevant services.

Treatment is achieved through individual or group sessions. The ability and the assessed capacity of patients is the basis of rehabilitation and patients are encouraged to utilise their own resources in the most effective way to achieve success.

To help recover independent daily routines, chores are introduced early. These include personal and instrumental activities of daily living. All patients are encouraged to take part in exercise and leisure activities.

This program would particularly suit young diagnosed people with Parkinson’s and older people (fifty to sixty-five years) in the diagnosis and maintenance stages (as described by Pathways) of the disease.

1.3 Kompassen, Lund

This is a community based assessment and rehabilitation unit for older people living in Lund. It is used as a stepping-stone from hospital to home or residential care.

The rehabilitation unit is a new concept and the team is comprised of a Doctor, physiotherapists, occupational therapists and nurses.

It is a short term, residential, functionally based rehabilitation program with specialised treatment for motor, cognitive skills and activities of daily living. It is not a Parkinson’s specific facility but it is the unit of choice for older people with Parkinson’s. Treatment started in the acute hospital will be continued at Kompassen.

The Functional Independence Measure (FIM) is the preferred assessment tool and patients are assessed on entry to the program, again halfway through their rehabilitation and at discharge. Patients are usually admitted to the unit for four weeks.

The FIM is discussed and completed by the team, thus developing the interdisciplinary approach. The team prepares the rehabilitation schedule. The main and sub-goals are set in collaboration with the patient and relatives, and the team meets weekly to discuss the patients’ progress. Each patient has a
care plan which available to them and their relatives and which documents the treatment plan in relation their identified goals.

Input from the relatives is valued and they are counselled to be realistic in their expectation, which is then reinforced, by their being involved in the rehabilitation process of their family member.

Families are given information and education to assist in optimising the patients’ independence when they are discharged home.

Kompassen places a high priority on self-management. Patients are provided with an information folder which contains the ward routine, their medication schedule (which they are taught to manage), an individual treatment schedule, transfer strategies relevant to their needs and information about techniques and aides which will enhance independence.

Specific treatment is given in motor skills training and activities of daily living.

Patients are taught to self manage personal care and instrumental tasks. The program focuses on functional independence with patients:

- Preparing meals for others on the ward
- Practicing cognitive activities eg discussion, word tasks, cultural activities
- Being involved in leisure activities
- Undertaking twice weekly community visits to shops (no matter what the weather) to practice money handling, mobility, planning, communication etc.
- Participating with group activities to develop interactional skills and motivation.

On discharge from Kompassen, ongoing care plans and the final FIM report are sent to community-based therapists. The occupational therapist, physiotherapist and/or nurse carry out home visits with community staff to assess environmental concerns and to address long-term management.

Kompassen will provide relevant training for the community care workers who will be supporting the patient after discharge, if this is required. These workers also spend time with the patients while they are still inpatients to maximise appropriate ongoing care support.

The Kompassen program with its self-management focus would best suit those patients in the diagnosis and maintenance stage (Pathways paradigm). Those moving towards the complex stage could benefit though would require greater post discharge support.
2. The United Kingdom.
2.1 Parkinson's Disease Clinic at The Mansion House Unit Of The Victoria Infirmary, Glasgow, Scotland

This rehabilitation program has recently won a best practice model award.

This PD Clinic is coordinated by a Geriatrician who works with the support of a Parkinson’s Disease Nurse Specialist. They then refer patients, as necessary, onto the relevant allied health professionals. The clinic accepts referrals from all age groups even though it is officially a Medicine for the Elderly unit.

The Consultant is very visible and available to the team and patients, creating a positive and empathetic atmosphere. After the initial appointment with the Doctor, the Parkinson’s Disease Nurse Specialist spends time with patients to reassure and reiterate any information about which they are not clear.

Patients are able to contact the clinic or the health professionals if necessary, without needing to wait for their regular three monthly appointments.

The staff believes that early referral, an interdisciplinary approach and regular access to the clinic helps prevent disability and deformity.

The physiotherapists and occupational therapists carry out joint assessments with particular interest in the patients’ skill in relation to transfers. The OT and PT will visit at home if the patient is unable to attend the clinic. Some patients are reluctant to come initially because of perceptions that the clinic may be confronting.

The overall aim of the program is to maximise potential, teach ownership and problem solving from the earliest stages.

All patients are given information about PD, medication, and rehabilitation, which they accumulate and file, in a personal folder over the course of their treatment.

Home visits are organised and home programs are provided as necessary.

There is a focus on the management of anxiety, and teaching problem solving skills, community living skills, maintaining mobility and relaxation techniques.

The therapists also conduct six week education programs and have introduced a monthly “drop in” afternoon at which patients can access the health professional on duty about problems and for advice.

The objective of Occupational Therapy as outlined for patients in an information sheet is:

To enable people to be as active as they would like to be within the limits of their condition while ensuring that both they and their carer remain within normal stress limits.

The aims of OT are to:

- Assist people to manage the practical aspects of daily life.
- To optimise function within the persons own environment.
- To retain independence for as long as possible.
To promote empowerment and assist people to develop their own coping strategies to enable them to deal with continuing change.

Provide the person with a sense of control over their life.

Assessment seeks to:

- Evaluate the impact Parkinson’s has on physical, psychological and emotional skills.
- Assess the pattern of symptoms and not the symptoms alone.

The occupational therapist does not use standardised assessments as none were found to be specific enough. The Canadian Occupational Performance Measure (COPM) was trialed but many patients were unable to recognise and articulate their problems.

Part of the OT role then is to assist/enable patients to recognise goals for treatment. Subjective measures are used to illicit information, with the OT then guiding patients to help them recognise and verbalise their difficulties with occupational performance. Areas addressed include:

- Functional mobility and self care,
- Eating and drinking,
- Productivity/work,
- Leisure/travel,
- Driving/transport,
- Home environment,
- Lifestyle planning,
- Education/support and advice.

The OT teaches problems solving skills. Part of this process involves providing the patients with equipment information/catalogues to encourage them to select what may suit their needs. The OT then discusses their choices with them before purchasing. Patients are encouraged to share their own solutions with other patients.

Patients are also taught techniques for relaxation and anxiety management, which frequently are early signs of PD. The belief being that it is best to commence the management of these problems early on in the disease process.

The OT leads, weekly, stress management and relaxation sessions during which the is on focus on breathing awareness, coping strategies, problem solving and tackling social withdrawal. Self-management is reinforced with patients learning how to use relaxation tapes and recognise stressful situations.

The tension/relaxation technique is used to assist patients’ self-awareness.

(The Physiotherapist also uses this technique thus providing consistency with strategy use.)

The OT has also found the stretch/relax technique useful with Parkinson’s. Appropriate tapes are provided for home use.
The staff also addresses the psychosocial implications, recognising that Parkinson’s changes patients and carers lives and has a major impact on future plans. Parkinson’s affects the entire family and subsequently the roles within the family may change. Following this focus, carers are understood to need:

- Recognition/acknowledgement.
- Understanding.
- Honesty.
- Reassurance.
- Encouragement.
- To be listened to.
- Practical and emotional help.

The Roll Over Education Program is run for two hours a week over a six-week time frame.

- The PD Clinic nurse presents information about the signs and symptoms and the common functional problems using an educational video produced by the Parkinson’s Disease Society.
- The dietician discusses the importance of dietary considerations in relation to nutrition, swallowing and medication.
- The OT presents sessions on stress management and relaxation and maximising potential.
- The physiotherapist discusses the benefits of exercise.
- The speech and language therapist provides information on voice and communication skills.
- The consultant geriatrician details the doctor’s diagnosis and medical treatment.

The PT treats individuals, provides home exercise programs and gives advice on specific issues. Patients can also attend weekly, hour long, hospital-based, exercise groups which run for 6-8 weeks. Participant numbers are limited to six.

The exercise group takes the following format:

- The first 15-20 minutes – seated work concentrating on rotation.
- Standing at a support – stretching, rotation, weight transfer.
- Pulleys and pedals for hip and shoulder rotation.
- Plinths for rotation, transfers and relaxation (Patients do not get onto floor because they have too much difficulty getting up.)
- Education and practice to help with transfers and sitting posture.
- Coordination and gait work.
- Relaxation.
To maintain the quality of the program, patients are encouraged to give feedback. The unit, also runs focus groups to establish patients’ needs and priorities and how to best address patient suggestions. Posters are then displayed outlining how the unit is responding to the issues raised by the focus groups.

The health professionals are developing a database for the rehabilitation treatment package, which will allow an audit of the system and an evaluation of its effectiveness.

2.2 Kirkcaldy – Whiteman’s Brae Hospital.
Fife Primary Care NHS Health Trust

Intensive Therapy Week.
The allied health team of this hospital are evaluating a project to assess the effectiveness of a week-long Intensive Therapy program aimed at minimising disability and maintaining independence through early intervention.
The eight patients selected for the program had diagnoses of 3–5 years and were in maintenance stage of the disease. Ages ranged from fifties to late sixties.

The program took place over five half-day sessions with input from the local PDS branch, a Consultant Physician, Physiotherapist, Speech Pathologist, Occupational Therapist, Dietician and social services.

A multi-disciplinary team including PT, OT, speech and language therapist, provided individual and group interventions and education. The program included carers.

Assessments, were carried out by each discipline and they were videoed following the guidelines designed by physiotherapist Rowena Kinsman at the Barnet General Hospital (Physiotherapy- 1986)

Video taped assessment has several advantages:
- Providing a visual record for future patient review.
- Allowing greater sensitivity to minor changes.
- Providing a forum for interdisciplinary discussion and intervention planning.
- The tape can be used as a tool to increase patient awareness of functional problems and so enhance treatment.

The physiotherapist assessed balance, mobility, gait, rigidity and rotation of the trunk and pelvis. Assessments included The Elderly Mobility Scale, Functional reach, Timed Up and Go, The Sharpened Romberg, One Legged Stance, 360° turn, sit to lie, lie to sit, sit to stand, gait, and a timed walk.

The patient was also asked to identify their main physical problems and how these impacted on their activities of daily living.
The physiotherapy daily exercise sessions which were held in the gym and the hydrotherapy pool, included:

- Supine knee rolling, pelvic tilting, bridging, arms in one direction and knees in opposite direction.
- Full stretch and full flexion, rolling left then right
- Prone kneeling/4 point.
- Lumbar work.

The role of the OT was predominantly concerned with teaching stress management and addressing carers’ issues. The OT assessment reflected these issues with the use of the Parkinson’s Disease Lifestyle Questionnaire - Age and Ageing Journal 1999. The OT also assessed writing skills but no specific functional issues.

When not involved in the Intensive Therapy Week, the OT uses the COPM assessment tool focussing on activities of daily living (ADL) skills.

The Speech and Language Therapist’s assessment, focussed on facial mobility, voice and swallowing. Assessed areas included:

- Frown – relax –5
- Yawn – stretch as far as possible (check for jaw tremor)
- oo-ee-oo-ee
- Press lips together tightly and puff up cheeks and release with a pah sound –check for lower lip weakness (dribbling) Check how much mobility and lip seal.
- Blow out air –it is timed.
- SSSS – keep it going for as long as possible- timed.
- AHHHHH – keep it going for as long as possible- timed.
- Read a passage (from a dysarthric standardised assessment) vocal range, speech, tongue movements observed)

Questions to the patient –

- Are there any restrictions to your communication?
- Does tiredness affect your speech?
- Are you bothered by any speech problems?
- How do feel when you are talking to people?
- Are you ever self-conscious when communicating?

(Early treatment of communication handicaps is recommended as they have a profound effect of self-confidence and quality of life.)
The carers were also interviewed about the person with Parkinson’s communication at home. This feedback serves to increase the therapists’ understanding of the communication style/problems experienced by the individual in their home environment.

- Is communication difficult between the carer and the person they care for?
- Does the person with PD have any difficulties with eating or drinking?
- Is there anything in particular that the carer would like to be addressed during the therapy week?

The Speech and Language Therapist conducted daily groups through the week and worked in conjunction with the Physiotherapist during hydrotherapy sessions. The pool “facilitates relaxation and as a consequence increases mobility. The acoustic environment and increased relaxation, also heightens vocal output.” Sheila Scott (Speech and Language Therapist/Education Coordinator –PDS)

The therapist holds the patient floating on their back with arms abducted and their head resting against the therapists shoulder. The patient breathes out through pursed lips while adducting their arms and abducts them as they breathe in deeply. (Practice of abdominal breathing is most successful in the hydrotherapy pool, in preference to sitting or supine lying.) Pursed lips breathing practice is used to increase respiratory volume and vocal intensity.

The speech sessions focus on breathing patterns, volume, rigidity in neck and shoulders and increasing patients’ awareness of any changes in their speech or swallowing function. Emphasis is placed on respiration, articulation, prosody, facial expression and strategies to improve communication difficulties.

The assessment and treatment of swallowing disorders is of critical importance as it is vital to establish a safe and functional swallow. The therapist also works with the OT to address issues of safe positioning and adaptive equipment.

2.3 St Martins Clara Cross Unit

St. Martins Hospital. Bath and West Community National Health Trust.

The Clara Cross Unit is a geriatric day hospital with access to an inpatient ward. Rehabilitation is holistic, the aim being to decrease the impact of the disease on quality of life. The PD clinic, held twice a week, uses an interdisciplinary approach with a geriatrician consultant, PT, OT and PDNS.

The ethos of The Clara Cross Unit is presented in the paper, Rehabilitation and the Interdisciplinary Approach – Dr. Dorothy Robertson MBCHB, FRCP, DCH, Consultant in Geriatric Medicine, Ana Aragon Senior OT, Gay Moore Senior PT and Liz Whelan PDNS (2000 – to be published).

The authors outline the basis for the concept of a continuum of care management in Parkinson’s Disease in preference to crisis management. While the development of new drugs has been emphasised
as the means to improving the outlook for patients with PD they suggest that more attention needs to be directed towards the organisation and delivery of care for these people.

Recent Parkinson’s Disease Society (PDS) surveys have shown that allied health professionals in the UK in 1997 saw less than 30% of people with PD. Often this access was only activated in response to a crisis situation. The traditional approach with its focus on pathology and drugs does not address the multiple functional problems experienced in PD. A variety of health professionals are needed to manage these issues. The authors outline the key role the Parkinson’s Disease Nurse Specialists (PDNS) have in facilitating multi-disciplinary input and coordinating care.

Rehabilitation must be holistic with a focus on function, the aim to reduce the impact of the disease on quality of life (QoL). The only valid outcome measure then is the perception by the patient and carer of their quality of life. The patient and carer should therefore be at the centre of the rehabilitation process.

The paper draws the differences between a multi-disciplinary versus an interdisciplinary team approach. Preference being for the latter, which involves health professionals working simultaneously, and cooperatively to evaluate and develop a joint action plans with input from the patient and carer.

The World Health Organisation’s categories of impairment, disability and handicap have been modified in recognition of the social aspects as well as the biomedical influences on QoL. The new terms are broader with:

- Impairment represented as body function and body structure.
- Handicap as activity limitation.
- Disability as participation restriction.
- In addition, is the concept of “well-being” which is synonymous with QoL and satisfaction with life. Well-being can be impacted by physical, social and patient expectations.

Rehabilitation should be directed at “activity” and “participation” and as such it requires a team of health professionals to improve patient perceived QoL.

The paper suggests the rehabilitation service should include:

- A mechanism for regular review within the care management plan.
- A specialist team, which is continually developing their skills.
- The team should include OT, PT, PDNS, a speech and language therapist, Social worker (SW), Consultant, Continence Nurse Advisor (CNA), and have access to dietetics, podiatry and dentistry.
- A care management plan, which treats the patients with in the context of co-morbidities, their medications, any cognitive, emotional and neuropsychiatric complications and carer needs.
- A key worker to coordinate the management of care and be a central resource person for patients and carers.
• An integrated patient file used by the team to facilitate information sharing and developing action plans within team case meetings.

The paper outlines rehabilitation strategies, which are based on shared team knowledge of the neuropathology of PD and of the role of the basal ganglia impacting on motor, cognitive and emotional function.

PD impairs the basal ganglia and supplementary motor area functions of planning and sequencing of well learned motor skills with appropriate force generation. The basal ganglia are also involved in cognition and mood through connections with frontal and limbic areas.

The rehabilitation process is complex, taking account of motor, communication, cognitive and emotional difficulties, symptom variation and pharmacological complications. The paper provides principles for a comprehensive assessment process, which recognises these issues.

The Pathways paradigm, the Primary Care four stage clinical scale, provides the basis for planning the rehabilitation process. This paradigm suggests that access by patients and carers to a specialist team provides them with the skills necessary to successfully manage PD and maintain optimum participation levels.

Treatment principles at the Clara Cross Unit are based on the research from the Kingston Centre in Victoria (Parkinson’s Disease: A Team Approach – Morris et al), which recommends a multi-sensory approach to facilitate movement strategies. Techniques include attentional focus, single tasking, and use of cues, breaking down sequences and structuring the environment.

Treatment is individual or group based with referral onto community services if required. As patients move into the “Complex” stage (Pathways paradigm), team input will be more intensive with the role of the key worker becoming more important in coordinating care. The paper suggests a day hospital is useful in assessing “Complex” needs as the patient can be observed through the day, allowing for the monitoring of fluctuations in function and drug reactions which are more common at this stage.

To illustrate the value of this approach two case studies are presented, one on the management of falls and the other on managing nocturnal problems, both of which have multiple causative factors that require a team of health professionals.

Additions to the present program provided by the Unit, which would improve the service include:

• A speech and language therapist, dietician and psychologist on the team.
• Another PDNS employed in the regional catchment area to increase the time the present PDNS can spend in the clinic.
• Another regionally based clinic to reduce the numbers seen at the Clara Cross Unit, thus improving service delivery.
• Increased carer education through specific education programs.
The PDNS visits all new referrals at home for an initial assessment using the Unified Parkinson’s Disease Rating Scale (UPDRS), the Mini Mental State Exam (MMSE), if appropriate the General Depression Scale, and a full history. If there are significant functional difficulties patients are referred onto the Clara Cross Unit for the team intervention. If the problems are mainly medical they are referred to out patients. The nurse will also refer patients on for continence assessment if this is identified as a need. The PDNS also provides some PD education and loans out the publication for people with PD, “Keep Moving with Parkinson’s” – Iansek et al (Kingston Centre-Victoria).

OT and PT treatment is individual or group based. Patients are referred onto community therapists if required, to manage home-care services and equipment provision. Patients can also be referred to the Primary Occupational Therapy Service (POTS) – which works solely in the community with patients needing short-term rehabilitation but not requiring hospital admission. The aim of this program being to maintain independent living in the community.

The role of the OT is in assessment and in providing individual sessions of education combined with training in the application of adaptive behaviours to enhance functional ability. Carers are invited to observe sessions to learn how best to encourage and enable optimum independence of their family member.

The Physiotherapist and occupational therapist both have funded research hours each week. The unit has recently applied to the PDS for funding to design and evaluate a training program for OT’s working with PD. The team also give presentations on this model to Medical and allied health professional meetings throughout the UK.

Occupational therapy techniques include:
(Framework of Intervention – Ana Aragon OT)

- A multi-sensory approach used to teach patients cognitive and sensory strategies so that they no longer rely on the “automatic pilot” of basal ganglia function. This method of intervention is often more appropriate than introducing aides and equipment which may be of limited value as the problems inherent in PD can complicate their introduction and use.
- Conductive Education techniques to facilitate function or movement, for example counting and verbalising an activity.
- Visualisation of successful activity completion as a preparation to activity.
- Re-interpretations of the negative self talk which impacts on functional ability through the basal ganglia link with the limbic system link.
Physiotherapy:

The PT works on an individual basis to improve balance through improving body awareness using the mirror and by videotaping sessions. This work is based on a study – Short Term Effects of Behavioural Treatment on Movement Initiation and Postural Control in Parkinson’s Disease: A Clinical Controlled Study.

This study concluded that behavioural treatment in PD might improve motor disability in moderately advanced patients. The Unified Parkinson’s Disease Scale and the Hoehn and Yahr assessments both indicated that changes (improvements) were related to the treatment methods. Data provided evidence that behavioural treatment, as a compliment to medication, can have significant beneficial effects on movement, initiation and forward postural bending during walking.

Exercise groups:

The PT and two aides lead two exercise groups a week, graded to match particular ability levels. Numbers are preferably limited to 10-12 participants. Patients attend the classes for approximately six weeks and are then reviewed.

The classes last an hour and are made up of predominantly seated exercises with some standing activities towards the end of the group. A less active group is held on a different day for the more disabled patients.

Exercise group format:
1. All call their names out using a LOUD voice.
2. Check sitting posture- feet flat on floor, lifted up in the back.
3. Breathe in through nose and say loud ahh
4. Shout help loudly several times. (Could be another word)
5. Facial exercise – wrinkle nose, lips- oo ee ahh, open eyes wide-shut tight, protrude tongue.
6. Practice swallow. (Discuss dribbling strategy – 1. keep head up 2. keep mouth shut. 3. consciously swallow.) Practice with fingers on the Adams apple to use as a sensory cue. Close lips and swallow and feel the movement up and down.. Instruction on swallowing tablets strategy and swallow before speaking.
7. Sitting posture. Straight and tall look over the persons head opposite.
8. Turning head L/R
10. Weight transfer in the chair.
11. R/L arm extension (stretch) count 12345 then down 12345
12. Lift bilaterally (12345) and extend wrists and flex elbows then push up against gravity (12345) and down (12345) - repeat sequence 5 times
13. Wriggle shoulders to relax them
14. 1. Link fingers together extended in front
2. Turn them through still extended
3. Lift up above head
4. Bring hands down behind neck with elbows extended
5. Release and bring them back down. Repeat 3 times. (For mobility, stretch and posture.)

15. Hands in prayer position with elbows out to the sides. Press together relax. (Increase flexibility of wrists).
16. Clench and stretch hands both movements strong.
17. Press thumb and fingertips together counting 1234.
18. Check posture again. Grow up through the back widen the shoulders and look over heads. Slump and feel the difference and straighten again.
19. Toe tapping with heels down alternating feet.
20. Tapping heels alternating stretching the ankle. Count 1-2 - 1-2
21. Marking time with high stepping 1-2 - 1-2. Stamping
22. Pointing toe into the circle with knee extended and pull toe back feel the calf stretch and the thigh contract. (Increase thigh strength for standing up walking.)
23. Getting out of chair strategy – discussion and practice.
24. Discussion and demonstration of clock turn. Move weight to L and step with the R foot when turning to the R. Opposite for turn to the L.
25. Rolling strategy demonstrated and discussed. Patients asked to instruct PT aide through process.
   1. Knees up.
   2. Lift and shift bottom to L.
   3. Turn head to R.
   4. Drop knees to R.
   5. Put arm over. Roll to R.
   6. Bring shoulders back to middle if going to lie on bed.
26. To get out of bed. Don’t move bottom across.
   1. Lift knees
   2. Turn head.
   3. Drop knees.
   4. Bring arm over and roll.
27. Round the circle high bean bag passes.
28. Throwing up beanbag and catching
29. Pass beanbag from one hand to other behind their necks under each thigh, change directions and behind low back – to help with dressing skills.
30. Finish by throwing beanbag into the middle of the circle.
31. All stand at parallel bars and sway to music with feet wide apart – balance.
32. PT dancing with some of group - waltz time.
2.4 Cambourne and Redruth Community Hospital, Cornwall Healthcare Trust

This is a hospital based PD clinic headed by, Consultant Geriatrician Dr D. MacMahon, who has a special interest in PD. The PDNS assists with the Clinic work. The hospital covers several PD clinics within the region. The PDNS does all the follow-up and support home visits and assists with clinic appointments.

The Unit has a multidisciplinary rather than interdisciplinary approach with the Doctor and/or PDNS referring to allied health as necessary.

Dr. MacMahon at this hospital first introduced the position of the Parkinson’s Disease Nurse Specialist. Since this inception, Dr MacMahon and Sister Rosemary McGuire (the first PDNS) have both been instrumental in developing the role, organising university training courses and working with the Parkinson’s Disease Society to have the nurses widely accepted through the medical community in the UK.

The PDNS university course was designed to be deliberately practical, because up-to-date there has been little interest/research into basic care management eg constipation in PD., drug side effect implications etc. The course also emphasises the importance of the multi-disciplinary team.

The hospital has recently funded a new nurse consultant position with time allocated for developing practice skills, supervising nurse led PD clinics and to lead the PDNS Team in the area. This new position will include research, for example, to develop guidelines/standards of practice to address problems such as falls prevention and low blood pressure.

The clinic based PDNS also has a role in running the local branch PD Support Group and the monthly Saturday Club. This Club is for people with PD, usually the more disabled patients, and their carers to attend for respite purposes and support. The PDNS uses the opportunity, to casually assess levels of function, coping and stress amongst the people and their carers. The Club also organises regular holidays for members, staffed by volunteers and the PDNS.

The local Parkinson’s Disease Society branch is very active in this area and has local medical practitioners and the PDNS on the committee. The committee organises regular health professional presentations at branch meetings. Improved PD education amongst members is vital to develop skills for coping with the long term management of PD. Self help skills are valued and patients and carers are encouraged to talk about their problems and the future, allowing the person with PD to have a say in their own future care requirements.

Occupational therapy.

The hospital OT’s intervene on an individual basis addressing functional ADL problems.
OT Assessment tools used include The UK Functional Independence Measure (FIM+FAM) (Functional Assessment Measure) - DR Lynne Turner-Stokes. lynne.turner-stokesdial.pipex.com
There is some interest in the Kingston Centre research and movement guidelines but the team does not use these universally.

The OT has trialed a Conductive Education Parkinson’s class. A group of six outpatients participated in exercises, which included sitting, standing, walking, hand and writing activities. The sessions were based on functional task analysis, and a breakdown of the movements into their component parts. The OT conductor facilitated movement using rhythm and counting.
The class was discontinued as the OT found the range of disability with in the participants made the class difficult to plan and manage. Participant feedback included the movement patterns not being perceived as normal movements and that the constant repetition/counting became monotonous.

Tai Chi Trial:
A Tai chi trial designed by Dr. Madeleine Grove MRCP - a Specialist Registra in Medicine for the Elderly - has just been completed. The aim was to evaluate the use of Tai chi as a simple, inexpensive, safe and effective physical therapy for Parkinson’s.
Tai Chi has well documented success with improving balance, flexibility and strength. The style of Tai Chi chosen for this study used elements of the Qi Gong breathing exercises and the first six movements in the Tai Chi for Arthritis form developed by Dr. Paul Lam in Australia.

The FICSIT trials (Medical Science Sports Exercise 1998) suggest that Tai Chi training positively effects overall life, with mental and physical improvements. It also achieves a high compliance rate for attendance and practice.
The objectives of the Parkinson’s Tai Chi trial were:
• To show that Tai Chi training is safe and well tolerated by people with Parkinson’s.
• To standardise a suitable program for patients with Parkinson’s.
• To demonstrate improvement in general well-being and motor performance in patients with Parkinson’s which is sustained beyond the intervention period.

The study was made up of twenty outpatients in the “Maintenance” phase (Pathways paradigm) of idiopathic PD. All subjects were independently mobile. The program consisted two groups of twelve weekly Tai Chi sessions, both groups having the same instructor. The sessions were videotaped. Assessments were carried out at recruitment and at three, six, nine and twelve months from baseline. Assessment scales used were the Get Up and Go Test, the Parkinson’s Disease Questionnaire (PDQ-39), a patient held log of falls, a self-rating scale (1-5) of tolerability, an instructor scale (1-5) of tolerability, and the Unified Parkinson’s Disease Rating Scale (UPDRS).
The results of the trial are not yet available but anecdotal reports from participants were positive and compliance with attendance was regular.
Expert Patients:
Dr Doug MacMahon (Cambourne and Redruth Hospital) and Sue Thomas (Royal College of Nursing) are part of a working party designing a PD specific Expert Patients Program based on the Chronic Disease Self Management Course developed by Kate Lorig. This is a generic course with a proven record for successfully helping participants regain, maintain or improve control over their lives. The program encourages a problem solving rather than a problem-focussed approach developing active coping skills.

Focus groups of people with Parkinson’s were part of the planning for the specific Parkinson’s information aspect of the course. This was followed by the implementation of a trial program to evaluate the course content and outcomes. Early in 2001 a trainer’s course will be offered, which will train health professionals and lay people to run courses within their local communities. The concept is based on the advantages of empowered and knowledgeable patients taking a more active role in their self-management.

The critical characteristics of an empowered patient were presented in a paper to the Sub-Group On Scoping The Program. (March 2000)
Empowered patients:
- Insist on being in control of their life.
- Use their intellect and imagination to find solutions to most problems.
- Know they have gifts and talents and strive to make use of them.
- Ask or seek help that is needed when it is needed.
- Have a realistic assessment of the impact of their disease.
- Manage the delay or minimise the effects of their disease.
- Recognise that getting worse as slowly as possible gives plenty of room for living.
- Accept some possibilities may be lost but look for new ones.
- Are confident in having a life to live and a contribution to make.
- Are able to balance their own needs with the needs of others.
- Regard health professionals as advisors and guides.
- Internalise good practice in health matters, mental and physical.
- Try to listen to others and expect to be listened to.
- Are more likely to explore different options for themselves.
- Have a good estimate of their own physical limitations.
- Have an understanding of the way symptoms or pain affects them.
- Allow themselves to be flexible.
- Tend to be outer directed people.
PD Exercise Group:

The hospital PT holds two outpatient exercise classes a week in the physiotherapy gym. One, a less strenuous class for the more disabled patients, with some participants sitting, but still using similar exercises to the format presented below.

The exercises are graded for difficulty; the number of repeats depending on the ability of the group members. The PT reports improvements in strength and balance with regular participation.

The PT also undertakes home visits to assess mobility needs and educate about home exercise programs.

Class numbers are kept to about twelve, the sessions last an hour and are held mid-afternoon. This class is a pure exercise group with no planned discussion/sharing time.

The format included:

1. Warm up in standing. March in a large circle to a taped march tune. Encouraged heel strike. Changed directions - think about the turn. Speed up. Instructed to swing arms. (Gait deteriorated with concentration on arm swing)
2. All face into the middle holding hands around the circle and marching on the spot, knees up as high as possible – L/R. All to the marching tune.
3. Hands joined R heel to middle with knee extended – in/out (5times) – repeat with R. Repeat again.
4. Next R foot taken out to the back/neutral/back (5) then repeated with L.
5. The R out to side and back – repeat with L (Quite wide stretch out.).
6. Sequence of forward/side/back (5) – repeat with other foot. (Heel down first.)
7. Throwing balls overarm randomly around circle – others try to catch.
8. Over passing bilaterally around the circle first to L then R – trunk rotation.
9. Throw randomly underarm
10. Form rows all facing leader. Check posture for a wide base, arms to side. Turning head to R the L - Head tilt feel stretch - chin tuck down..
11. Arms at sides take weight onto balls of feet then roll weight towards edges/sides/back/sides/front. (To increase awareness of the weight moving around the feet and balance) Check posture.
12. Hands on shoulders - bilateral shoulder circles and change direction.
13. Shoulder shrugs
14. Lift R arm in extension above head as coming down lift the L. Alternate.
15. Hands tucked under arms lift L extending the elbow – return hand to underarm. Repeat 5 then R side. Then both together and back - out/back (5)
16. Unilateral arm movements - forwards /back/out to side/back/up/back. R/L (5)
17. Side stretch down with arm extended to R then return – repeat with L.
18. Swinging arms – Bilateral twisting - Don’t drop body forwards.
19. Now all use long canes (6ft), held vertically in midline - lift up onto toes then back onto heels.
20. Feet flat cane in front on the floor 9 (vertical) bend both knees and push bottom towards floor – keep feet flat on floor then rise up.
21. Holding onto something stable and the cane stand on 1 leg and bend as before on the supporting leg - then rise and repeat with other leg.
23. Standing up straight feet apart holding cane horizontally bring cane to shoulder height then stretch out in front with extended elbows and then lower to hip height then lift straight up to above head.
24. Holding cane horizontally, lift cane up above head stretch / stretch out in front/lift up.
25. Swinging cane from side to side reaching as far up as possible.
26. Cane in midline walk hands all the way to the top and then down again. Climb the cane towards the ceiling with the hands, and then back to the floor.
27. Use thin floor mats, (Airex) some have pillows. Start in high kneeling and walk towards the front of the mat – then walk backwards on knees.
28. All fours and back arch/slump.
28. All fours - lift R arm out to side with elbow extended and watching so get head turn as well. Repeat with L.
29. Then R arm extended forwards and L leg extended backwards - out 2345 / back 2345
30. Sit back on heels with arms extended - stretch.
31. Prone lying - feet up/down - ankle extension/flexion.
33. Alternate knee bends to chest.
34. Both knees bent up and knee rolls, with shoulders kept flat.
35. Rolling strategy practice to R/L.
36. Bridging
37. Flatten legs, arms by side – lift R arm up above head stretch and return Alternate arms then lift both in stretch.
38. Relaxation in supine. Starting with breathing. Body scanning technique used beginning with the feet moving towards the head.
2.5  The North Tyneside Parkinson’s Disease Services
Northumbria Healthcare. NHS Trust, North Tyneside Council.

“If Parkinson’s disease is a journey then your pathway of care is all about making sure that you get the help, support and treatment you may need at each point on that journey”
- North Tyneside Parkinson’s Disease Services.

Managed Care: A Multi-disciplinary Care Pathway and Care Program for Parkinson’s Disease.
This project was originally funded as a trial project through the PDS. This service recognises the individual variability of PD patients that necessitates a range of services, which are flexible and allow access when required.

“The right care and treatment at the right time from the right person”
- North Tyneside Parkinson’s Disease Services.

Patients and carers are central to this approach and are actively involved in the process.
The program developed from the growing understanding of the benefits of therapy and of access to social services and the PDNS, that many people with PD were not able to access these services and nor were there protocols for organising and coordinating the services.

The Care management Team is made up of:
- The Parkinson’s Nurse Specialist.
- The Physiotherapist.
- The Speech and Language Therapist.
- The Consultant/Hospital Doctor.
- The Social Worker.
- The Occupational Therapist.

The new service now provides:
- Medical treatment and supervision and advice particularly concerning medication.
- Information and education programs about PD and its’ treatment.
- Access to the whole rehabilitation team at the appropriate time.
- Advice and support from the specialist nurses.
- Continuity of care
- Good communication between hospital and community services.
- A key worker to provide a single point of entry and to coordinate care throughout the course of the disease.
- Patients with a personal resource file used as a record of care and information.
- Patients receive a comprehensive “Users Guide” to the treatment process.
• A professional version of this guide to the treatment process is provided to hospital and community health staff.

The approach focuses on:
• Individualising treatment.
• Individual and small group therapy.
• Easy access to the program.
• Coordinated care.
• Empowering and educating the patient and carer.
• A team with specialist knowledge.
• Allowing time for patients to discuss problems with staff.
• Ongoing support.

The key worker is seen as pivotal to the smooth coordination of the care process throughout the course of the disease.

Patients and carers are provided with an information and resource file, which allows them to have their own record of care and to store information about their treatment and the service. Also included is a comprehensive guide to treatment of the most common problems associated with PD and the care pathway. Appropriate facts sheets, from the “User’s Guide” resource, are given to patients as required. A professional version of this guide is sent to all the team members, including general practitioners, community nurses, hospital wards and departments.

The patient information file encourages patient and carer ownership and partnership in the care management program. The file is made up of sections outlining:
• The team approach
• The pathway of care
• The role of the key worker.
• The roles of the care management team.
• Contact details of the team.
It also contains:
• An explanation of the purpose of the file.
• Space for collected information.
• The patients’ assessment and identified problems.
• A personal record of care.
• Communication sheets for team members.
• A use of service sheet – to note contacts with staff concerning PD issues.
2.6 The Role of the Parkinson’s Disease Nurse Specialist.

Parkinson’s Disease is progressive but within its progression it is highly variable, the degree of disability fluctuating unpredictably. Medical intervention must be individualised as it too increases in complexity with disease progression. Access to support to manage these and the many other complicating physical, psycho-social issues is critical to maintaining quality of life.

The PDNS has the ability to provide such a service liaising with other health professionals and maintaining close contact with patients and their carers. Their main goal is to improve the quality of life of people with PD and their carers.

The first Parkinson’s Disease Nurse Specialist was appointed to the Cambourne and Redruth Hospital in 1989 on the initiative of Dr. Doug MacMahon. In 1992 a partnership between the Parkinson’s Disease Society and various pharmaceutical companies, further developed the position, throughout the UK.

There are now over seventy working PDNS throughout the United Kingdom and the PDS is aiming to increase these to two hundred in the near future. The PDS is also working to standardise the specific training courses that are offered through particular universities. These courses are also being adapted to educate other allied health professionals about PD.

In the UK, PD management is carried out through hospital-based clinics, which have either a consultant neurologist or geriatrician leading a multi-disciplinary team, with the PD Nurse Specialist playing a pivotal role. Some PDNS work alongside the consultants, increasing the time available for patients and carers to discuss issues and to be alert to the need for referral onto other health professionals. PDNS with their holistic view of the patient are ideally placed to help lessen the problems the disease can present. Increasingly their value is being recognised specifically around disease management and education of carers and health workers. They work in a variety of settings including the PD clinics, general practices and in the community, where they do follow up and support home visits. They also visit residential and respite facilities and they work with already existing multi-disciplinary allied health teams.

An evaluation project based at St. Mary’s Hospital, Paddington London, is assessing the cost effectiveness and health outcomes of community PDNS care in nine health authorities in England. Preliminary data show that the introduction of these nurses has proved very successful. They have directly assisted patients and their families with:

- Medication and managing the complications of therapy.
- Liaising with doctors.
- Linking people into appropriate services at an early stage.
- Providing counselling, education and support.
• Helping to develop self-help skills and knowledge at an early stage of the condition.

They also have a broader role:
• Educating GP’s, hospital staff and residential care staff.
• Running community awareness programs.

The role of the PDNS must necessarily be flexible, requiring strong communication, management and planning skills, and the ability to keep up with and implement relevant research in order to maintain best practice.

A seminar held in 1996 “Managing Parkinson’s, Making The Difference” at the University of Manchester concluded that major improvements in quality of life for people with PD and the social and economic burdens on the carers can be achieved by:
• The empowerment and education of patients and carers.
• Regular assessment of health and social care needs of both patients and carers.
• The planning and organisation of consistent and individualised care, particularly in the early stages of the disease.
• Effective co-ordination and collaboration between primary and secondary care multi-disciplinary teams.
• Early access to specialised nursing skills.
• Selective use of acute therapies.

The PDNS can be an invaluable resource in achieving these outcomes.

Jane Mills, a London based PDNS reports that “patients feel supported and also more secure because they have more information to handle problems as they arise so they don’t panic”.

2.7 Continence Services in the United Kingdom

In Parkinson’s Disease autonomic dysfunction, which causes amongst other difficulties, “constipation and urinary problems … can present significant difficulties to the person and their carers” (Elderly Care 1999)

The Royal College of Nursing Continence Care Forum in the 1997 document The Cost of Continence states that:
• Incontinence is a major problem that affects all age groups.
• Incontinence is not a social problem but a symptom of one of several underlying treatable conditions.
• All clients have a right to appropriate and effective treatment of their condition regardless of where they live and what they can afford.
• There should be mandatory minimum standards of continence care based on clinical need.
  - Sue Thomas, RCN Community Health Advisor.

It is recognised that continence issues are common in PD, as a consequence of the condition itself, the anti-Parkinson’s medication, mobility and dexterity issues, poor nutrition, and decreased fluid intake/dehydration, which can be symptomatic of underlying swallowing problems.

Incontinence significantly increases the risk of hospitalisation and failure to manage continence problems can result in psychosocial problems, isolation and increasing dependency, the chance of falls and carer stress. All of which are recognised as risk factors for people with PD.

Continence issues are often raised with the PDNS within the security of the supportive relationship. Patients can be referred to continence advisors through the PDNS and other health professionals. Continence flyers are available in PD Clinics.

The Parkinson’s Disease Society has produced specific continence information and advice booklets in conjunction with The Continence Foundation, Hatton Sq. London.

The Clara Cross Unit (Bath) provides free continence information packs, which clearly and simply discuss common bowel and bladder issues and suggestions for management, including seeing the Continence Advisor. These information packs educate people to what is considered a “problem”, making them more likely to seek help. This approach is in line with the emphasis on self-management principles and the “Expert Patient”.

The educative approach increases general awareness, thus addressing the points raised in the paper “Good Practice in Continence Services” (Department of Health 1998 UK) that people with incontinence issues may be:
• Embarrassed and often ashamed of their condition, keeping it a secret.
• Reluctant to seek help within the family and need encouragement to seek advice from health professionals.
• Unaware of the treatments available to cure or manage their condition.

In 1998 the Continence Foundation as part of the National Awareness Campaign, produced The Healthy Bladder Campaign, The “Do It Yourself” Guide to Local Publicity. This guide documents the steps to take when launching a continence program and as such could be useful for similar programs in Australia.
2.8 Complimentary Therapies

The UK does not have community based therapy services so rehabilitation is predominantly medically based. However there is growing interest in complimentary therapies having a role in the holistic management of PD. Those presently in practice are Tai chi, Conductive Education, The Alexander Technique, massage, art therapy, and exercise and relaxation techniques.

As a complimentary extension to traditional therapy for PD, these techniques may produce positive results and even if the benefits are only relatively short lived, they could have a place as a palliative measure for those who enjoy the process.

2.8.1 Tai Chi

Tai chi, already has well documented success by improving balance, flexibility and strength. The Tai Chi trial at the Cambourne and Redruth Hospital was designed to evaluate the effectiveness of Tai Chi in improving mobility in PD, especially in relation to decreasing the risk of falls. More information on this trial is documented in the section on the PD Clinic at the Cambourne and Redruth Community Hospital.

2.8.2 Conductive Education

Conductive Education is a rehabilitation system, which originated in the 1950’s. It is also known as the Peto System. The Centre for Conductive Education (CE) in the UK is in Birmingham. CE claims success in helping people with PD, improve mobility and their skills with activities of daily living (ADL).

CE aims to teach people with movement disorders, strategies to overcome the problems associated with neurological damage. It is based on active learning rather than passive treatment. It involves learning methods of controlling the motor symptoms. These methods, called tasks are then transferable to everyday activities.

In PD movement is still present but it cannot be accessed. CE looks for a key to unlock movement. CE cannot cure PD but offers a method of controlling the motor symptoms. Techniques are taught within a structured environment so that they can be adapted by the person with PD and included in their everyday activities.

The program is conducted in a group format. There is flexibility within this process to cater for individual needs. Age and length of diagnosis vary and all group members have individual goals. Participants continue with their regular medical treatment whilst on the program.

Classes are comprised of fifteen sessions, held once or twice a week for two hours. The first hour and a half is the structured program. The final half hour is discussion time with staff during which group
members may share experiences. The group process promotes a positive atmosphere, which motivates, supports and facilitates compliance and self esteem.

The leaders or “conductors” are movement specialists whose role is that of educators. The main symptoms of PD, which are addressed in the program, include bradykinesia, tremor, rigidity, freezing, and dyskinesia, lack of facial expression, micro-graphia and speech difficulties. CE focuses on the conscious learning of all aspects of skill attainment – the cognitive, emotional, social and motor elements. Participants learn groups of “tasks”, (this term is used in preference to “exercises”) which relate to the particular skills required to perform movements and which can be adapted to suit different activities.

The “conductor” verbalises the tasks and uses counting (1-2-3-4-5) and rhythm to facilitate initiation, breathing, attention, concentration and movement. The program consists of lying, sitting and standing tasks within which are included both gross and fine movements. Postural tasks are included to assist with transfers and mobility. Facial tasks work on expression, breathing and communication.

CE places importance on their conductors understanding and having knowledge of PD and its impact on daily living. The conductors are then also able to provide participants with education and support. CE endeavours to maintain the persons’ sense of control throughout this educative process. with participants also benefiting from increased self confidence, motivation and general well being.

**Conductive Education – Kew Gardens, London.**  
**Integrated Neurological Services – Multiple Sclerosis, Parkinson’s Disease, Stroke.**  
**Kew Baptist Church, Windsor Rd. Kew.**

In the UK patients have only short-term rehabilitation contact with the National Health Service, they are then discharged. Consequently, those with chronic, degenerative conditions frequently do not receive adequate support. The Integrated Neurological Services, started in 1993 as a Charitable Trust, is a means of filling the gap. The program is staffed by an employed Coordinator / Physiotherapist and a volunteer SW and OT. Participants pay to attend the group. These funds are then used to finance the continuation of the group.

The Parkinson’s CE program is held Mondays. The morning group, 10.30am-12.30pm for the more able (Diagnosis - Maintenance stages – Pathways Paradigm) followed by an afternoon group for those who are less able (Complex stage – Pathways Paradigm). The aim is to maintain functional everyday activities by relearning movements and function through task performance facilitated by rhythm and counting. The therapy process is orientated to thinking about the whole person and their activity needs with in their 24-hour day.
The group, of approximately ten participants, starts with a general discussion about the past week and problems etc. The group is very supportive of each other and creativity in problem solving is encouraged. Group members use the phrase “Come to your senses” – which means increasing awareness of their body and its position in space.

Each group member has a health record book, which they are encouraged to keep up to date themselves, recording their medications, any treatments and side effects, and falls etc.

After the discussion, the session starts with seated activities at the table, to facilitate upper limb function. The PT who directs and counts the tasks leads the group.

Then they progress to the floor work using thin mats of raised plinths if people cannot get down onto the floor.

The participants receive home visits if necessary to assess and modify their living environment. The OT can manage to organise small equipment requirements, with the client paying the costs, but if there are a significant requirements, the person is referred to the Social Services.

Tasks:

1. Seated with hands flat on table, elbows extended. Clients visualise their posture and weight bearing to become symmetrical. Stretch up the spine, shoulders level and head in midline.
2. Clasp hands, stretch up and reach behind the neck
3. Stretch up and turn hands in/out while clasped.
4. Standing against the wall - Hands clasped, stretch up above head out in front, behind neck and stretch elbows back to wall.
5. Hands on hips and lifting knees up in a march to turn around on the spot.
6. Facing wall - slap the hands up/down the wall to full reach and back to shoulder height – bilaterally and individually.
7. Hands against the wall extended up - rock weight back and forth.
8. On floor – use chair to get down onto knees then walk on knees backwards before going into side sitting and supine.
9. Stretch out in all directions. Awareness of body position - weight awareness. stretch spine, widen shoulders. Rock chin loosely from side to side. Abdominal breathing
10. Hands on mat and stretch thumb out to the side.
11. Relax facial muscles. Relax body parts individually.
12. Warm up exercises-leg lifts, counting 12345
14. Breathe-lift R leg, then breathe –lift L (As breathe in lift and as breathe out lower.)
15. R arm and leg abducted and alternate with L
16. Alternate R arm and L leg abducted then change.
17. Lift head up 123 down 123-Turn to R 123-turn to middle 123 then L 123
18. Bend up knee to chest and clasp 12345 then L knee to chest- then both and rock in that position.
19. Lift head towards knees then lower then lower
20. R heel to L knee then alternate then change quickly on the command “change”.
21. Bend up R knee and then stretch up-bend1, lift2, and down 3, straighten 4.
22. Hands supine/pronation – bilateral large movements encouraged. Over1, down 2, then R and L individually.
24. Toes up, palms up-toes down, palms down. R toes up, R palm up then change.
25. Make a fist/stretch out paying attention to extending the thumb.
26. Knees lifted to chest and lift toes up/down then circling the feet.
27. Rolling knees to R/L 12345. Roll knees as far as possible.
28. Hands behind head and knees up – open out elbows-bring knees together the alternate.
29. Massage all around the face with hands. Small circles around eyes, cheeks, lips, chin.
30. Close eyes tight, open. R open/close then L.
31. Tongue in/out into R cheek then L.
32. Eye movements up/down R/middle/L.
33. Tongue to R cheek and look to L with eyes then change
34. Press lips together and relax. Move lips to R the L – alternate.
35. Twist hands over and back to the count of 1-2.
36. Bend up knees and stamp feet alternately.
37. Clasp hands and bring to R shoulder then to L 1-2.
38. Hands clasped and arms extended and roll to side.
39. Lying on their sides - Side leg lifts then forwards/backwards.
40. Alternate top arm forward and top leg back as far as possible.
41. Alternate arm forward and leg back. Roll onto back and do same on other side.
42. Roll onto back -bridging and side buttock lifts.
43. Bend up knees and roll onto side and over to prone.
44. In prone stretch arms forward. Stretch whole body.
45. Make fist/open with arms extended –1-2.
46. Hands behind neck and lift elbows alternately then together.
47. Stretch arms forward again and bring heels towards bottom with toes towards the floor. –1-2.
48. Alternate and change then both knees up together. Point toes up/down –1-2.
49. Straighten legs 12345. Arms stretched out lift hands up/down 1-2.
50. Push up on hands trying to straighten elbows and push back with hips and onto knees.
51. Hands on waist walk towards the chair on knees. Hands on chair, lift up R knee then L knee - crouch- stand up – turn – sit down.
52. Sitting extend leg with heel on floor and tap it out to the R then to middle the L out. Press thigh down with hand and lift leg to straighten knee. 1-up 2-down.
53. Cross legs over 12345.
53. Sit forward in chair. Swing R leg to R-twist body to R then Swing L leg to R (so sitting sideways on chair) then bring each leg back to middle and repeat on opposite side.
54. Lean forward with hands on hip and stand up.
55. Stand behind chair with hands on back (use ladder back chairs)
56. Back onto heels then toes up /down.
57. Stand in circle. Stretch arms down open /close fist 1-2
58. Wide step to R then to L 1-2, then step forward with heel down first then toe – very deliberate. Exaggerated march in circle then turn to other direction using marching step turn. Knees up high. Clap to turn.
59. Exaggerated march with large arm swing R leg L arm
60. Long strides with arms swinging across the body.
61. Marching in 2 long lines up to and around a chair on either side and return.
62. Sitting at table with hands out flat, stretch fingers one at a time.
63. Supination/pronation 12345 (try to get thumbs to touch table)
64. Push into table to extend elbows and develop strength.
65. Fist to shoulders, stretch up open hands/stretch forward and close.
66. Hands up to shoulders, then above and alternate with forwards
67. Making fists with thumbs extended – bilateral then alternate.
68. Extend fingers one at time. 12345
69. Lift hands up/down off table, forearms resting on table. (Wrist work)
70. Rolling chopstick between hands with elbows extended.
71. Walk thumb and first finger up the stick, and then repeat with other fingers. (Straight elbows)
72. Face – eyebrows up/down frown, wrinkle nose.
73. AEIOU
74. Tongue twister practice – members can suggest twisters.

Some negatives in relation to the session:

- The tasks were too complex at times – multi-tasking.
- The counting and instructions were too fast so that full range was hard to achieve.
- Some tasks were too difficult to manage.
- Some tasks could be made more effective if used in combination with the Kingston Centre PD movement strategies.
- An understanding of the neuropathology of PD was not utilised in the task performances.
2.8.3 The Alexander Technique – London.

This program teaches people to re-educate themselves to use their bodies correctly, “concentrating on process rather than results” (Dr. C. Stallibrass - Alexander teacher)

The PDS and the Foundation for Integrated Medicine, is at present funding a research study comparing The Alexander Technique with massage to evaluate their ability to improve movement in PD. The “Hands On” project is a large controlled trial to measure the effects of lessons in the Alexander Technique and Therapeutic massage on the management of disability by people with Parkinson’s. Massage was used to act as a control for the touch and attention received during The Alexander lessons.

The “Hands On” trial was held at The Centre for Community Care and Primary Health (CCCPH) at the University of Westminster, London in the University Polyclinic. (The CCCPH is committed to the integration of complementary medicines into mainstream NHS primary care by providing clinically based professional training and research programs.) The research project which was conducted between October 1999 and October 2000, was by Dr Chloe Stallibrass and Ms Peta Sissons (Project Coordinator)

People with PD, who were responsive to levo-dopa therapy, were invited to participate. These volunteers received lessons in The Alexander Technique or therapeutic massage (over a twelve week period) or were part of the group who received neither intervention. All participants continued with their normal PD medications.

Participants were assessed at the beginning, mid way through and at the conclusion of the trial. Assessments included three short questionnaires and two timed tests. The assessments used were The Modified UPDRS (Measuring activities of daily living - ADL), the PDQ 39 (A PD quality of life measure), the Beck Depression Inventory, and body concept. The main focus of the trial was on ADL performance.

An initial pilot study for the project, indicated that people with PD, on completion of a course of Alexander lessons, reported:

- Less difficulty performing daily activities.
- Improved movement ability.
- More positive feelings about themselves
- Less feelings of depression.

(DR C. Stallibrass)

Past students have also reported, an increased feeling of control over their condition that was in addition to benefit they received from their drugs and a sense of “lightness in their bodies.” The
lessons helped to replace worries about what “might” happen with positives to improve movement and balance in the “immediate” time. (The Parkinson Autumn 1999)

The Alexander Technique promotes conscious thought with all movement, the aim being to decrease unnecessary tension, which interferes with good balance and movement. The technique shows people how to unlearn “bad” habits of posture, balance and movement and become conscious of every movement they make, sharpening the link between body and mind.

Treatment is on an individual basis. The teacher utilises verbal advice and gentle manual guidance helping the person to develop more of a sense of self in space. With practice, people become increasingly aware of how they are moving and thinking which facilitates a reduction in the tension and stress held in the body.

A course of lessons includes twenty-five sessions as well as exercises to practice at home. (The Parkinson - Autumn 1999 - PDS quarterly publications)

Anecdotal reports to date are positive in relation to the effectiveness of Alexander Technique in improving mobility and function. Reports following the massage sessions were indicating positive feedback with increased relaxation and less muscle tension but only in the short term. The results of the project will be available early in 2001.

(Society of Teachers of The Alexander Technique. 20, London House. 226, Fulham RD. SW10 9EL)

2.8.4 Massage

Traditional Therapeutic Body Massage was used as an alternative in “The Hands On “ Alexander Technique trial. Those participants receiving massage, all reported positive short-term benefits in flexibility, mobility and relaxation but these benefits did not last past a few hours.

Massage has also been offered as part of the services provided by the PD society in Christchurch New Zealand with similar results.

The UK Parkinson’s Disease Society through its publications has articles on the benefits of therapeutic massage and other similar techniques e.g. Bowen Therapy, Reflexology and Reiki as alternatives therapies to compliment mainstream medical management. (This information is offered for general interest not as recommendations and readers are advised to discuss any treatments with their doctors.)

Massage stimulates the skin, underlying tissues and muscles through applied pressure and stretching. Slow rhythmic movements are used generally in PD to help decrease rigidity, loosen tightness and reduce tension and stress.
The Bowen Technique involves gently manoeuvring the muscles and tendons. It utilises light touch and can be administered through clothing. The frequent pauses between moves allows the body to benefit from each set of Bowen movements. The practitioner can target a specific area or the whole body. Recipients experience general feelings of heightened well-being and relaxation.

Reflexology follows the principle that certain parts of the feet or hands correspond to other parts of the body and that stimulation of these areas can have a relaxing effect on the whole body. This is accomplished by restoring the natural equilibrium, which is considered to be out of balance as a result of the disease process and stress. Feedback from people with PD, receiving reflexology, indicates improved quality of life through the easing of some of their symptoms.

Reiki employs the laying on of hands to reduce stress and enhance relaxation. It is an holistic treatment inclusive of the body, emotions, mind and spirit. The practitioner lays hands on a number of specific points and the position is held for five to ten minutes. It is said to decrease stress and increase the ability of people with Parkinson’s to cope with their condition.

2.8.5 Art Therapy for Parkinson’s Disease

Art for PD is new to the UK, and the PDS has this year (2000) funded a trial group facilitated by Nancy Tingey, the originator of the Painting with Parkinson’s Art group in Canberra. Mrs Tingey is an Art teacher and curator who on receiving a Churchill Fellowship in 1997 travelled widely (Italy, UK, USA) investigating the therapeutic benefits of art for people with PD. She and her husband, who has Parkinson’s, have returned to England and she is now developing Art for Parkinson’s in the UK.

The results of the initial pilot Art Project have been very positive with improvements in the physical and emotional status of the participants. The number of art groups in the UK is now to be expanded and a Coordinator of Art for Parkinson’s is to be created within the PDS.

Art therapy sessions, held several times during the YAPMEET (The Young Parkinson’s Conference held in Peterborough in June 2000.) were enthusiastically attended. Many participants reported initial hesitance but this soon disappeared as Mrs Tingey drew them into the pleasure of experiencing art.

In support of the use of non-traditional creative therapies in maintaining wellness, a recent study on mice showed the possibility of reducing the impact of neurological disease (Huntington’s Disease) by providing the mice with an enriched and stimulating environment.

Participating in Art for Parkinson’s is:

- A well accepted “normal” creative activity.
- Enjoyable.
- Available to people of all ages and backgrounds.
- Requires no previous experience.

Art for Parkinson’s provides the opportunity, within a structured environment for participants to learn a new, or rekindle a previously enjoyed, leisure interest. Art allows the opportunity for participants to express emotions, and to exercise their creativity, which in turn stimulates their intellectual and cognitive skills.

The art sessions, provide the benefits of group social interactions, giving participants the chance to regain confidence with communication (which is often a significant problem), within a supported, relaxed environment. Art can also provide the chance to share a common interest with a partner or carer again, if both attend the group thus perhaps reducing stress within the relationship.

Art can be adapted to suit varying levels of skill and physical ability, for example, the use of wide handled broad brushes which allow easier grasp and a pleasing result that does not rely on fine stroke work; different techniques can be used if one style does not suit a person’s particular abilities – texta, crayon, collage, dots, lines etc; using wet water-colour paper with a ware-colour wash provides an attractive result with minimum effort.

The art teachers’ and/or the students’ imagination and ingenuity enhance participation in the experience of art.

The choice of teacher is important, the person needing to be experienced, enthusiastic, and willing to experiment. The teachers’ role is to encourage participants, through the medium of art, onto the pathway towards recovering their self-confidence and enjoyment in life.

The benefits of Art for Parkinson’s are many and include:

- A new enjoyable interest.
- Improved eye-hand coordination.
- Improved hand function
- Increased concentration.
- Mental stimulation.
- Increased opportunities for social interactions.
- Reduced social withdrawal and isolation.
- Improved ability to relax and manage stress.
- Reduced anxiety.
- Reduced levels of depression.
- Raised self-confidence.
- Increased feelings of self worth.
- Improved quality of life.

2.8.6 Exercise Classes

Exercise, as part of holistic management, is recognised as having a role in PD, to maintain/increase physical status and function. All the programs reviewed use similar exercise routines, but there are no universal exercise protocols. There is a need then, for research to provide evidenced-based programs to ensure best practice when specific Parkinson’s exercise groups are offered.

Exercise is used widely in PD programs to improve the strength, flexibility and balance deficits, to assist with mobility and transfers and to help improve co-existing physical conditions. The effectiveness of exercise sessions, either individual or group can be confounded by the variability and unpredictability of function common in PD, particularly as the condition progresses. Other limiting factors include age range, co-existing conditions and cognitive ability to follow instruction and/or demonstration.

In Sweden, at Rehabcentrum, exercise is prescribed individually with programs designed and supervised by the PT, using gym equipment, the hydrotherapy pool and functional activities eg transfers and gait. At Kompassen, the emphasis is on traditional physiotherapy intervention as required, with the emphasis on mobility practice taking place in functional settings both in the Rehabilitation Unit and the community.

In the UK there is a mixture of individual and group programs run by the PT. Some groups are graded according to ability and all vary in the number of participants. The most successful included practice with purposeful activity and balance.

The physiotherapist in Kirkcaldy ran similar individual programs, to those at Rehabcentrum in Sweden, during the Intensive Therapy Week. Group classes were held daily through the week with much of the focus on rotational movements and transfer techniques.

In Glasgow, the Mansion House Unit, while providing individual physiotherapy interventions as required also conducts six to eight week blocks, of weekly exercise classes.

The Clara Cross Unit in Bath has two weekly exercise groups, held in six to eight week blocks, which are graded for ability, one being more vigorous than the other. These groups also include education on movement strategies based on the Kingston movement guidelines eg rolling and bed transfer strategies.
In Cornwall at the Cambourne and Redruth Hospital, the physiotherapist conducts an ongoing weekly exercise class in the gym. This quite strenuous group concentrates on general flexibility, lower limb strengthening and a great deal of balance training.

The Tai Chi Classes also held at this hospital provided exercise for flexibility, strength and balance within the “forms” rather than through set static exercises. This type of exercise could be regarded as more functional as it combines the practice of balance accompanying purposeful movement and is more likely to be transferred to everyday living activities.

The Conductive Education Classes (Cornwall and London) also promote increased flexibility, balance and mobility through the conducted “tasks”. These classes are primarily focussed on improving functional activities rather than as specific exercises to improve physical status.

The PD group in Christchurch, New Zealand, utilizes the skills of an exercise physiologist together with the physiotherapist, to assess clients and plan relevant individual programs. The TEAM Centre is the venue for individual and group work, using the gym equipment, while following individual exercise prescriptions. The emphasis is on strength and flexibility. Home or gym based programs, using community gyms, are designed for individuals if appropriate and if they wish to continue their exercise routines away from the TEAM Centre.

The exercise physiologist or physiotherapist also conduct an ongoing weekly group exercise class for those not able enough to cope with the more vigorous gym work.

2.8.7 Relaxation Training

Relaxation techniques are widely promoted through all the programs as a part of stress management and to help cope with the emotional consequences of PD. Anxiety and depression are common in people with PD and many experience panic attacks.

These problems can be related to medication and mobility fluctuations, the connections between the basal ganglia and the limbic system, as a reaction to the diagnosis and/or the resultant social and financial consequences, and the stresses involved with living with the progressive condition. These emotional problems often occur early on in the disease process and it is therefore important to recognise and address them as soon as possible to maximise effective self-management.

Medication can often be helpful with the new antidepressants less likely to complicate the motor symptoms. Changes in the anti-Parkinson’s medication can sometimes also help alleviate some of the emotional issues.

Counselling is useful, helping people identify problems and possible solutions. Learning strategies to deal with anxiety and depression provides patients with a sense of control over their lives. Self-management skills training combined with relaxation training provide useful tools to improve quality
of life. Specific relaxation techniques include breathing exercises, progressive muscle relaxation, body scanning and guided imagery.

In Glasgow, at the Mansion House Unit of the Victoria Infirmary, the OT’s approach to stress management included problem solving, maximising potential, anxiety management techniques and the regular use relaxation tapes. The OT’s conduct hour-long relaxation training sessions with a focus on, coping strategies, tackling the issues of social withdrawal, breathing techniques and progressive tension/release relaxation. The physiotherapist provides continuity by using this same technique to finish the weekly exercise classes.

This program is based on the techniques documented in The Relaxation Therapy Manual, written by Christine Heron and published by Winslow press 1996.

Most exercise classes finished with relaxation and some programs provided self-made relaxation audiotapes for home practice. The physiotherapist leading the exercise class at the Cambourne and Redruth Hospital uses a body scanning technique with participants lying on mats.

Tai Chi through its emphasis on harmony, even controlled breathing and an inward centring focus promotes calmness as part of the total experience.

Carolyn Noble, the PDNS in Peterborough, uses the Snoezelen Sensory Room to enhance and teach relaxation skills. The sensory stimulation used includes visual, auditory, olfactory and physical, in the form of a vibratory chair or plinth. This technique has been very successful for the patients with whom she has worked.

In Kirkcaldy, the OT provides the sessions on relaxation and stress management, during the Intensive Therapy Week, for both the people with Parkinson’s and their carers. The physiotherapist and the speech and language therapist use the warmth and support of the hydrotherapy pool in preparation for teaching the abdominal and pursed lips breathing techniques, both of which are part of the relaxation-training program.

All techniques use the concept of the power of the mind and its ability effect the body, teaching patients that they have the capacity to relieve their physical stress and emotional distress. Relaxation exercises assist to increase self-awareness of body tension and then teach how to actively relax that tension in a systematic way. All programs encourage daily relaxation sessions at home and the setting aside a particular relaxation time, recognising the need to reinforce learned strategies through regular practice.

Parkinson’s is a very complex condition and the best care management requires a multidisciplinary health team approach and complimentary therapies, also have a positive role in contributing towards improved quality of life.
2.9 The Parkinson’s Disease Society of the United Kingdom

“People with Parkinson’s lose the ability to plan ahead because of the unpredictability and variability of the disease. They can take back control of their lives by increasing their education in relation to the disease and the medication, by meeting with others and by believing there is a life beyond Parkinson’s”.

- Mary Baker, Chief Executive - PDS.

The PDS plays a major role in the UK in the management of PD. The aims of the Society are:
- To help patients and their relatives with the problems arising from Parkinson’s.
- To collect and disseminate information on Parkinson’s.
- To encourage and provide funds for research into Parkinson’s.

Services include:
- Education - providing educative material to people with PD and their carers, health professionals and care workers. The current education focus is on matching the needs of people with Parkinson’s at all disease stages with education programs for health workers, to improve treatment standards and quality of life including care management in residential care facilities.
- Confidential help-lines – Three PD nurses are available five days a week.
- Welfare Visitors – The PDS trains and coordinates Welfare Visitors who are attached to local branches. These visitors provide support in the community working with the branches, families affected by PD, government and voluntary organisations.
- Carer Programs – these may be single days or weekends where carers get together for education and support.
- Holidays – designed for people with PD and carers. Special needs are catered for.
- Residential care information database – The PDS is involved in developing high standards of practice in residential care and providing information on facilities in local areas.
- Intensive Therapy Week programs – Therapy, education and social activities are provided for people with Parkinson’s.
- YAPP&RS – The Young PD group was formed in 1987 in response to the particular needs of young diagnosed people. This group now has over a thousand members in various sub-branches and they hold a bi-annual conference with a scientific, therapy and social program.
- Funding research – Medical research includes surgical and pharmacological treatments and Welfare Research focuses more on functional quality of life issues. Information is available on all present research in the publication Seeking Solutions, produced by the PDS.
- Ethnic and minority groups – Special programs for these disadvantaged groups are presently being evaluated. The Outreach Service for Black and Minority Ethnic Communities employs Information officers who provide advice, information and support.
- Advocacy – Lobbying for improved standards of care and continuing research. The PDS uses the media, advertising and information materials to improve the general public awareness of PD.
• Fund raising – Providing financial support for all the services provided.

Future Plans:

• Creating a “flying squad” of care workers who could maintain a person with PD at home in an emergency, until the most appropriate care is organised, if their primary carer cannot care at that time. (eg The carer is admitted to hospital in an emergency.)
• PD web site to be created with validated information available on line.
• Increased funding for research into complimentary therapies and quality of life.
• PDS to work with pharmacists to set up a drug information line.

2.9.1 PDS Research

SPRING is the official Special Interest Group for medical Research, constituted within the Parkinson’s Disease Society. SPRING supports the PDS having a high research profile in promoting the search for improved lasting therapeutic treatment, for research into better drugs, to find a cause for PD and to prevent PD.

The PDS in conjunction with other funding bodies provides grants for medical and welfare research.

The members of the SPRING committee, which is made up of both professional and lay people, have responsibilities to coordinate working groups in the following areas:

- Gathering information on medical research.
- Fund raising.
- Publishing news and reports in everyday language.
- Discussion forums.

The SPRING Website is www.spring.parkinsons.org.uk

The Medical Research through 1997-99 focussed primarily on surgical and pharmacological interventions, gene therapy, stem cells and epidemiological studies. The aim is to increase understanding of the disease process and influence strategies for the treatment of PD.

A project measuring dopaminergic and serotonergic function in people with depression and PD recognises the frequency of depression and how it increases the degree of disability experienced by patients. This study hopes to identify chemical changes leading to depression in PD and provide a rationale for treatment. This research is particularly relevant to the findings of the recent PDS Global Survey, which reported that half the people surveyed were suffering with depression and that depression has a major impact on perceived quality of life.
Another project is presently focussing on the management of dyskinesias, resulting from long term levo-dopa use, without an accompanying loss of motor function. The results will be relevant to the goal of maintaining quality of life in the face of advancing disease.

The Welfare Research grants through 1998-99 were related to function and quality of life and provide guides to improving treatment strategies. These included:

- Strategies to improve bed mobility.
- Evaluating the needs and availability of services in the community for young diagnosed people.
- Carer’s perspective of the impact of falls.
- Visual hallucinations and their impact on patient and carer.
- Development and evaluation of an information pack and patient needs monitoring form for the management of PD.
- Understanding how women with PD cope with menstruation and associated gynaecological problems.
- Evaluating the effects of the Alexander Technique on management and disability.
- Managed care: evaluating the impact of a multi-disciplinary care pathway and the care program approach in PD.
- Drooling – Objective measurement and response to therapy.
- The management of patients with PD – The identification of early stage movement, speech and swallowing problems.
2.9.2 Young Alert Parkinson’s Partners & Relatives – YAPP&RS

A missed connection

She lay in Mineral Muscle Soak
Soaking her minimal muscles.
Bugger!
This body would not arrive in time.

Ladies and Gentlemen
We apologise for the delay.
It appears there is a spot of bother down the line.
A question of neurons not connecting with receptors.
There is no body available at the moment.
All other bodies are having their tea.

When her body arrived,
Dried and reconnected,
It clocked in
Later that day
And did overtime.

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YAPP&RS and SPRING Member

The Young Alert Parkinson’s Partners and Relatives (YAPP&RS) was founded in 1987 in response to the identified needs of about thirty six young couples in their thirties and forties. Mary Baker, the then Welfare Director of the PDS, formed a focus group and a steering committee to establish the YAPP&RS. The group soon had over four hundred members.

By 1991 the YAPP&RS had become sufficiently independent to organise their own conference, the first YAPmeet. This was held in Peterborough with two hundred registrants. (The PDS provides funding to help subsidise YAPmeet participants’ costs.)

The concept was taken up in Europe with the Dutch forming their own Young Onset Group in 1993, called the YOPP&RS. In 1994 the YAPP&RS hosted the first EURO-YAPmeet. This meeting was attended by young onset people their partners and families and neurologist from nine different countries. There have now been three EURO-YAPmeets, held in Germany, Denmark and the Netherlands.
The YAPP&RS has an educational role with a focus on self-help. They publish a quarterly YAPmag, providing up to date information to young people and their families, and fact sheets on specific young onset issues. They have established a web site and produced an educational video, “The Uninvited Guest”.

The group also conducts major fund raising events, such as the Bordeaux to Barcelona Bike Ride. There are now twenty-six YAPP&RS groups in the UK with over thirteen thousand members. These groups, which operate under the umbrella of the PDS, vary from those, which are purely social to those providing educational sessions.

The YAPP&RS has highlighted the special needs of young diagnosed people and that the management of these issues may have to be met in different ways to those of older people. Younger people with Parkinson’s will have work and family commitments, social, emotional and relationship issues which may be more complex and made more fragile with the stress of a challenging degenerative disease. These people will experience the disease for a longer time, having to cope with the accumulative complications of long-term therapy at a younger age. They need to maintain their optimum independence and stay in control of their lives by learning about the condition, its treatment and daily management techniques using the latest technology to stay in touch with new research and developments.

The 2000, fifth biannual YAPmeet, titled “Education, Consideration and Understanding” reflected these needs.

Presentations and workshops included:

- A Neurological Overview
- Hidden Problems (Autonomic and emotional problems)
- Updates on Drugs and Surgery
- Speech therapy
- Newly diagnosed Issues
- Living Alone with PD
- The Psychological Effects of PD on Children
- Benefits and Employment
- Painting with PD
- Counselling
- Male Sexual Dysfunction
- Carers Forum
- Role of Education
- Gene Research.
Note form reports of two of the presentations from the 2000 YAPmeet in Peterborough follow:

2.9.2.1 Non-Motor Problems Associated with Parkinson’s Disease.

Dr Marie-Helene Marion,
St George’s Hospital

Autonomic problems impact on quality of life and there is very little research on this subject. The non-motor problems which are part of the degenerative process of PD evident in the autonomic nervous system include: Pain, constipation, nausea, loss of weight, insomnia, dizziness, drooling, nocturnal sweating, hot flushes, skin oiliness, dermatitis in the midline of the face, white scurf in the hair.

Pain.

Pain can

- Occur at the onset of the disease eg. Sciatica/frozen shoulder.
- Accompanying the motor fluctuations associated with advancing disease, in the early mornings, associated with diphasic drug reactions with or without dyskinesia, with off periods (cramps and/or burning sensations), with nocturnal akinesia.
- Occur with on period severe cervical spine dystonia or pain without dystonia.
- Accompany joint pathology changes – shoulder, lumbar spine, knee, and postural alterations. People with PD are more susceptible to scoliosis and kyphosis (important to stretch spinal muscles).

Pain is more frequent in young onset. It can be correlated with motor fluctuations, can be poorly localised, intermittent, and predominant on more akinetic side. Amitriptyline can help with pain from contracture if given in very low dose.

Patients become very scared of hospital admission because the staff may not understand nighttime problems/pain and their carers are not available to help them.

Sleep Disorders.

- Fragmentation of sleep causes fatigue for the person with PD and the partner.
- The sleep regulation mechanism is involved in the degeneration of PD.
- About 50% of people with PD are affected.
- It is common for people with PD to have insomnia in the second part of the night.
- Associated factors are nocturnal akinesia, nocturia, and depression
- Disruptive nocturnal behaviour is common – fight, scream, hallucinate. People with PD do not remember the event the next day. This is very disturbing for the carer. (Some dopamine agonists can trigger this.)
- Nocturnal myoclonus – jerkiness in sleep, which disturbs the partner.
- Sleep problems can also be related to restless led syndrome. (RLS)
Some people have kicking movements associated with RLS – cant keep legs still need, have to get up frequently or have legs moved for them which is very disruptive to them and partner.

Anti-Parkinson’s drugs can impact on pain and sleep – L-dopa and agonists can cause drowsiness, amantadine & selegeline should not be taken in evening because they are stimulating.

Dopamine agonists can cause drowsiness and night-time disturbances.

Amitriptyline has helped some with sleep disorders to restore the correct sleep pattern.

Melatonin can help return the sleep cycle - to reset the internal clock do not go to bed before 9pm and spend time outdoors in the sunlight without sunglasses. Do not nap for more than 1-2 hours after lunch.

Gastrointestinal system

- Excess of saliva – not due to increased saliva rather a reduction in swallowing frequency. (Botox treatment to relax the muscle to stop it contracting and producing the saliva.)
- Other common problems reported are: dysphagia, nausea, abdominal bloating and

  Dysphagia:
    - Prevalent in about 50% of people with PD. The oesophageal phase of swallowing is affected. (Decreased tongue function and decreased efficiency causes a slowed swallow)
    - Weakness in the lower oesophageal sphincter causes gastroesophageal reflux.

- Constipation:
  - Very frequent problem.
  - Two types identified: slow transit and outlet syndrome.
  - Sometimes constipation can be severe, also time consuming.
  - Associated factors: dehydration, diet, and insufficient exercise.
  - Anti-Parkinson’s drugs all can cause constipation, except entacapone, which can cause diarrhoea about 6 weeks after starting on the medication, must discontinue the drug if this occurs because the diarrhoea is usually very severe.
  - May have alternating constipation/diarrhoea that is actually background constipation.

- Urinary symptoms:
  - Problems include: Nocturia, frequency, urgency, detrusor instability, decreased detrusor capacity, anticholinergic agents.
  - Constipation is often connected with urinary frequency/urgency

Dizziness

- Fifty percent of people with PD experience orthostatic hypotension (patient must lie down for 3-5 minutes, then take BP at one minute and 3 minutes after standing up)
- Often reported when getting up in morning, and after meals. (Big meals in particular), after exercise, can happen very quickly.

- Treatment of hypotension – sleep with head raised by 2 pillows and a pillow between the bed and mattress, have smaller meals, hydration with fizzy drinks and caffeine, coca cola very good, support stockings are totally unrealistic because they are too difficult to put on Check for hypotensive drugs eg some antidepressants

- Fludrocortisone can help but can risk supine hypertension if the drug dose is too high - can cause CVA.

Sexual problems.
  - Hyper sexuality is more common in men - Increased libido with impotence.
  - Behavioural symptoms - exhibitionist, dis-inhibition, and inappropriate behaviours.
  - Can be related to dopamine agonists.

2.9.2.2 Quality of Life

Dr David Burn, Consultant Neurologist

- Impairments - direct neuro-physiological consequences of the underlying pathology.
- Disability - functional (behavioural) consequences of any pathology or impairments.
- Handicap – social consequences of the disease specific to personally relevant issues. Handicap is the area, which is often overlooked by the doctors.
- Health outcomes = Biological & physiological variables (symptoms-functional status-general health) & overall quality of life perceptions.

Measuring Quality of Life:
- Generic measures – Sickness Impact Profile (too long), Nottingham Health Profile (insensitive), SF36 (Short Form) not appropriate for older people because of work questions.
- Disease specific measures –PDQ39 - This measure has 8 dimensions and 39 items. – mobility - ADL - emotional wellbeing-bodily discomfort – stigma - social support – cognition – communication.
  Scores 0 = best. 100 = worst
- Bodily discomfort and emotional wellbeing do not correlate necessarily with the length of time of the illness.
- The Global Parkinson’s Disease Survey (PDS 1999):
  Six areas were covered:
  Communicating the diagnosis - the patients’ emotional state - access of patients to information and contacts about their illness -use of holistic therapies - access to and use of support groups - clinician’s use of holistic treatment provision of information.
  Standard clinical assessments also assessed: general health problems, quality of life, depression, disease severity, dementia, and the burden of caring.
Only 17.3% of quality of life (QOL) perceptions were explained by the degree of difficulty associated with medication and the stage of disease.

58.2% of variability in QOL was related to levels of depression.
The survey found that few people recognised that they are depressed.

Depression:
Depression has 40-65% prevalence within the population of people with PD.
There are effective treatments available for depression in PD.
Assessment of PD treatment effectiveness can be confounded by depression. Patients may not report effectively on treatment outcomes.
Doctors may not recognise the depression because of the PD symptoms and so patients do not receive effective treatment for their depression.

Barriers to diagnosis of depression:
- Disorder related – lack of symptom specificity and criteria.
- Patient related – attribute symptoms to physical illness and negativism.
- Physician related – focus on the physical illness and lack of time.

Criteria to diagnosis of depression:
- Affective – decreased mood and interest.
- Cognition – negative, decreased conversation.
- Behaviour – impact on daily function, interferes with daily living.
- Physical – decrease appetite, loss of weight, pain, difficulty sleeping.

Diagnosis requires:
- Four symptoms for at least two weeks.
- The symptoms are not a direct consequence of other drugs.

There is higher prevalence of depression in PD than in age-matched controls.
There is no correlation of the prevalence of depression with the severity/duration of the disease.
Often depression may be evident years before motor symptoms appear.

Neurochemical changes cause susceptibility to depression.

Pathology:
May vary and may be multifactorial.
Studies show decreased metabolism in the caudate nucleus and orbito frontal cortex. (The caudate nucleus is involved in cognition). These areas are under-active in depression in PD.

L-dopa- can increase depression.

Treatment:
- Counselling
- Drugs - there have been few studies to evaluate efficacy and tolerance.
Selective serotonin reuptake inhibitors (SSRIs) do not have anticholinergic side effects. They can be activating so need to be used with care if patient is agitated. They may cause some worsening of PD symptoms. Avoid co-prescribing with selegiline.

Tricyclic antidepressants - Nortriptyline helps with sleep. Amitriptyline - blocks reuptake of noradrenaline and serotonin. Has a mild effect on tremor. Side effect - dry mouth, decreases blood pressure.

- ECT can be effective for very deep depression. Lifts depression and also temporarily improves motor symptoms.

Sleep disturbances:
Sleep problems have a highly negative impact on QOL and are a major determinant in caregiver stress. Impaired nocturnal sleep may occur early in PD. REM behaviour sleep disorder can appear before PD is diagnosed.
74-98% patients affected.

Autonomic disturbance can cause sleep problems – nocturia etc.
Sleep fragmentation and insomnia are more frequent in PD.
Excessive daytime sleepiness – 25% of people with PD experience.
Many sleepy patients deny somnolence

Unexpected sleep episodes are relatively rare and can be identified by history. They are usually an extension of excessive daytime somnolence.

Increased somnolence in PD. occurs with all dopaminergic drugs and is dose related.
(Agonists - Pramipexerole and ropinerole, L-dopa, selegilene, apomorphine can all cause sleepiness.)
Medication – co medication especially psychoactive drugs with anti Parkinson’s drugs. Responds to clonazepam.

The Epworth Sleepiness Scale (Assesses sleepiness during the day.)
- Sitting and reading
- Watching TV
- Sitting, inactive in a public place
- As a passenger in a car for one hour without a break
- Lying down to rest in afternoon
- Sitting talking to someone
- Sitting quietly after lunch without alcohol
- Sitting in a car while stopped for e few minutes at traffic lights (as the driver)

Score:
- 0 = would never doze
- 1 = slight chance of dozing
- 2 = moderate chance of dozing
- 3 = high chance of dozing

Maximum of 24
Autonomic problems:
Impact on QOL (very little research on this subject.)
Sweating, hot flush, skin oiliness, dermatitis in midline of the face and white scurf in the hair. (Tricyclic antidepressants can increase sweating.)
PD may not be well controlled.

Medication and QOL:
GP’s are crucial to integrated care management of PD.
Sinemet will always work if given in correct way. Effectiveness is masked by its absorption from gastrointestinal system. This modulates the effectiveness of the drug. As PD progresses there is a very narrow window to get the dose right or dyskinesias result. These are more difficult to manage in later stages.

Apomorphine is supervised by the PDNS. Apomorphine pumps can manage the PD symptoms well for 8-10 years. Then there is an increase in dyskinesia, on/off phenomenon and decreased responsiveness. (Apomorphine pumps are now maintained while patients are having surgery.) To treat nodules dilute apomorphine with 50% saline. Can also inject into abdomen, shoulders – less nodules form in these areas because of the increased movement. When the needle is removed, massage the area to move the excess apomorphine under the skin.

Amantadine decreases dyskinesias for 18months – 2 years then looses effect. On stopping amantadine can have severe increase in stiffness (rebound effect) Used with people over 70 years, it can cause hallucinations.

Nausea:
Patients with PD are easily nauseated which can be related to delayed gastric emptying and the anti-Parkinson’s medication. The only anti nausea medication that is safe is domperidone. Dispersible tablets are easier to take and keep down if patients feel nauseous.

How to get the most from the appointment with the Doctor:
- Get there on time
- Ask questions about the hidden symptoms because if doctor cannot see the problems he/she may not enquire about them.
- Note down any questions to be discussed.
- Keep a diary to note how feeling.
- If nervous and speech slow best to prepare in advance.
2.9.3 The Education Department of the Parkinson’s Disease Society

Sheila Scott, the National Education Coordinator, presented an overview of the Education department, at the 2000 YAP meet in Peterborough.

The aim of the Education Department, is to tailor education programs to meet the needs of all those who are involved in PD - People with PD, carers, health and social service staff, pharmacists, undergraduates and voluntary agencies.

“Marrying needs to professional learning” (Scott 2000)

Education is considered crucial to improving services and ultimately the quality of life of people with PD and their families. Part of the departments’ role then, is to listen to all relevant groups and to respond to their concerns and requests for information. Areas of focus for the Education department include:

- Increasing general public awareness about PD.
- Making sure that any information that is produces is clear and visually attractive.
- Improving quality of life by having people with PD presenting the key messages about factors, which influence quality of life, to students of the health care – Medical an, allied health students.
- Training for Doctors to develop skills in relation to the initial telling of the diagnosis. (The “telling of the diagnosis” was reported as a common area of concern by The Global Parkinson’s Disease Survey)
- Developing protocols and educating staff to improve the experience of hospital admissions for people with PD.

The Education Department has the responsibility to:

- Disseminate any new research findings relevant to the management of PD.
- Maintain the flow of accumulated information out to people with Parkinson’s, carers and service providers.
- Access and have input into professional development courses relevant to PD.
- Devise new educational training resources.
- Reinforce models of good practice.
- Highlight issues affecting quality of life.
- Provide quality resources for:
  - Distance learning (Nurses and allied health professionals)
  - Assessment tools
  - Customised education templates
  - New course development
  - Focus groups
  - Models of good therapeutic practice.
A practical example of the potential of the department would be, the education and training of general practitioners and residential care nurses in the detection of the early signs and symptoms of PD and in the making of appropriate referrals. (Caroline Noble PDNS 1998).

To maintain this service the department must constantly:

- Collect and collate new information.
- Be alert to problem areas and management issues.
- Seek models of good practice.

The PDS then, through the auspices of the Education department, has the opportunity to play a role in influencing clinical practice, shaping government standards, creating and maintaining interest in all areas of PD, building networks of expertise and enabling the sharing of views, information and techniques.
3. Christchurch, New Zealand
3.1 Parkinson’s Disease Society

Christchurch, New Zealand

The Parkinson’s Disease Society in Christchurch is affiliated with the Multiple Sclerosis Society, sharing the same premises and support staff. It is a community-based program financed through fund raising and Government grants.

The Society provides:

- Confidential free and individualised service to people with Parkinson’s and their families.
- A home visiting program.
- Specialised programs and support for newly diagnosed people.
- Up to date information for members and their families on treatment, research and practical coping issues.
- Information for and liaison with health professionals.
- Fitness and exercise programs.
- Support groups.
- Workshops for professionals and clients.
- Live-in recreation and workshop programs.
- Advocacy and information on benefits and community services.
- Public education and information.

Staff:

- The Services’ Director/Coordinator, Dianna Jackson, is a physiotherapist. She is responsible for coordination the service, providing counselling, fund raising and health education. This includes the production of the STEP Reports – The Support Through Education Program. These are information bulletins for health professionals working with PD, people who have PD and their families. The reports are produced quarterly and cover medical issues, drug treatments, common problems, quality of life issues etc.

  The STEP Reports are now distributed nationally through the New Zealand Parkinson’s Association, Information Service.

  The coordinator also is responsible for fund raising, giving workshops and lectures on PD throughout New Zealand and providing educational reports for local and national PD newsletters.

- The Director of Support Services is responsible for contacting and assessing all new referrals and for the supervision and co-ordination of the Field Officers social services team.
The three Field Officers are involved with home visiting and providing support in the community, and also assisting with carer issues. The Field Officers are registered nurses but are not specifically Parkinson’s Disease Nurse trained and cannot intervene with medication issues.

An Exercise Physiologist works the Physiotherapist to plan exercise programs on an individual and group basis.

Exercise Programs:
Exercise is increasingly being recognised as important in PD to improve the general health and wellbeing, and to maintain/improve physical and functional status.

The current focus of the exercise program, in Christchurch, is to individualise exercise prescriptions specific to the particular needs of the clients. The great variability of function experienced by people with PD, suggests that “general” non-specific group exercise sessions may not able to provide precise enough exercise programs to meet individual needs.

The PD Society has established a Therapy Exercise Assessment and Management Centre known as the TEAM Centre as a venue for the new exercise programs. The TEAM Centre is focussed on maintaining and optimising mobility. These specific sessions will be carried out in small groups and participants will also be given programs to undertake at their local community gyms if appropriate.
A small general exercise group for those unable to manage the more strenuous individualised exercise program continues to be held weekly in the Centre.

Assessment for the exercise program is based on the guidelines researched at the Kingston Centre in Victoria, as are the strategies used to facilitate movement. The assessment has a functional focus and goals are client driven.
The levels of function/disability over eighteen areas are assessed, including – medication, personal ADL, instrumental ADL, communication and psychosocial status. This holistic approach then allows action to be instigated to meet specific non-exercise needs as well as highlighting overall exercise goals.
General exercise outcomes would include increased strength, flexibility and balance with transfer across to improved activity of daily living skills.
Participants requiring referral for other allied health interventions are sent onto the hospital or community based private therapists, as New Zealand does not have community based allied health therapy services

Equipment used in the TEAM Centre includes a treadmill, dual action cycle, wall bars, active/passive trainers, therapy balls, hand weights and a pulley weight machine.
People attending the TEAM centre can self refer or be referred by health professionals based in the community, local hospitals or by the PD Society.
The TEAM Centre program is based on the work of Elizabeth J. Protas, PT, PhD, FACSM et al (American College of Sports Medicine), documented in a paper outlining exercise recommendations and implications in relation to Parkinson’s Disease. The authors report that their clinical experience does support the use of exercise to improve function in PD even though very little objective evidence is available.

The Authors’ report that complications to exercise for people with PD include:

- Autonomic issues such as disturbances of thermal regulation.
- Postural changes
- Akinesia
- Postural instability
- Timing of medication
- Medication side effects impacting on exercise tolerance and performance
- Psychosocial factors eg depression
- The increasing complexity of the disease/treatment process.

As PD progresses so do the direct functional consequences of the disease (eg tremor and rigidity) and the indirect consequences (eg de-conditioning and decreased range of movement) and the composite effects (“a combination of direct central nervous system changes and compensatory musculoskeletal symptoms”).

Exercise may have little effect on the direct symptoms of PD but appropriately designed programs could positively impact on the indirect and composite consequences of the functional problems.

The Authors suggest that exercise for PD cover five categories:

- Flexibility
- Aerobic training
- Functional training
- Strengthening work
- Motor control

They also recommend the definition of specific exercise goals, as different interventions will have different outcomes.

As PD is a chronic progressive condition exercise needs to be regular and ongoing. The suggestion is that general flexibility can be maintained with weekly activities, whereas posture maintenance requires daily exercise.

There is support for the use of individual goal directed programs within group settings. The benefits of social interaction and increased compliance inherent with a positive group process should be
considered when planning for people with Parkinson’s, as they tend to withdraw from social interactions.

“Live-in” Week Programs:
The PD Society also organises yearly “Live-in” Week programs where people with Parkinson’s and their carers participate in a week of activities including exercise, education, socialising and trying out new interests.

Participants need to be continent (or able to independently manage any incontinence) and preferably ambulant or able to transfer with minimum assistance.

PD Society staff members and volunteers staff the “Live-in” Weeks.

These programs are held in local country conference facilities, which are able to provide a range of amenities to suit the proposed program of events. Activities in the past have included exercise groups, pool sessions, spouse groups, quiz nights, hot air ballooning, sing-alongs, and horse riding.

Participants come from all over New Zealand to attend these weeks.
4. Conclusions and Recommendations
Giving people with Parkinson’s a future and not just a past.

4.1 Key Strategies - Sweden, the United Kingdom and New Zealand

- The critical role of education – People with PD, carers, health professionals, carer workers.
- Staff with a special interest in PD.
- The need for an holistic approach to effectively manage Parkinson’s.
- The long term benefits of early referral to treatment centres.
- Benefits of PD Clinics. – Geriatrician led and providing continuity of care.
- The effectiveness of interdisciplinary teams to manage multiple issues.
- Coordinated, seamless care management.
- The use of interdisciplinary files and joint goal plans.
- Recognition of the impact of non-motor problems impact on quality of life.
- The critical role of Parkinson’s Disease Nurse Specialist – medication management, support, referrals, education.
- Functionally based therapeutic interventions.
- The role of evidenced based practice in ensuring best practice models of care management.
- Funded research and development time for clinical staff to evaluate intervention strategies.
- Quality of life as the relevant outcome of all interventions.
- The role of complementary therapies in maintaining/improving quality of life.
- Patient/client held Care Management Records to increase the sense of ownership of the care process.
- Self-management skills training - The Expert Patients Program.
- Exercise – the role it plays in reducing falls and increasing mobility and independence.
- Stress management strategy training.
- Addressing the special needs of young people with PD.
- Addressing carer needs.
- Addressing the needs of minority ethnic groups.
- Improving the standard of care for people with Parkinson’s in residential facilities.
- The powerful role of PD support groups in providing advocacy and support.
Planning for the Positive Management of Parkinson’s.

4.2 Influencing Factors:

- An increasing older population.
- Medical treatment is palliative – no prevention, no cure, no alteration to progress.
- Demand for services increasing:
  - 1% of the population over 60 years diagnosed.
  - 2% over the age of 70 years diagnosed.
  - Approx. 10% of all diagnosed less than 50 years.
  - Higher frequency diagnosis.
- Under-recognition and under-servicing of needs of both patients and carers.
- Poor coordination of services.
- Multiplicity of issues – motor, autonomic, cognitive, emotional, social, carers.
- Increasing management complexity with length of diagnosis and medication use.
- Increased risk of falls: de-conditioning, postural changes, impaired balance/mobility.
- Increased frequency of admissions to residential facilities.
- A variety of health professionals and services are required to manage the condition.
- The health care team, to be effective require a high degree of knowledge and interest.
- Services are required intermittently and at irregular intervals for the duration of the disease – follow up is critical.

4.3 An ACTIVE Approach.

To successfully address the needs of people with Parkinson’s and their carers it is necessary to adopt a positive and proactive approach to the continuum care that is required to manage Parkinson’s. To do this, I believe we can learn a great deal from these overseas models, drawing on their shared and innovative ideas to utilize for program development in Australia.

ACTIVE Management Incorporates:

- **A** = Access to medical specialists/clinics with up-to-date knowledge
- **C** = Coordinated pathways of care management
- **T** = Therapy – early referral to PD specific allied health services
- **I** = Interdisciplinary teamwork
- **V** = a Voice – Client input into treatment and self-management
- **E** = Education at all levels
  - Evidenced-based practice
4.4 **ACTIVE** Management Recommendations:

- Parkinson’s Support groups and people with PD must advocate for the early referral to Parkinson’s services by medical and allied health professionals. This will facilitate planned management rather than crisis response.
- Introduce the Parkinson’s Pathways paradigm (MacMahon and Thomas) to all general practitioners and specialists (geriatricians and neurologists) to facilitate improved care management.
- Facilitate easy access to services to more effectively manage the unpredictable variability of PD, to encourage patient responsibility in the treatment process and to provide ongoing support.
- Establish PD Clinics in major hospitals to more efficiently manage the multiplicity of problems and to effect referrals to Therapy Services for ongoing management.
- Establish the role of the Key Worker to facilitate and coordinate care pathway planning for individuals through the management process.
- Introduce Parkinson’s Disease Nurse Specialists to educate patients, provide support, and assist with medication and disease complications. Establish PDNS training courses into the Specialist University Nursing Programs.
- Provide up to date and ongoing education programs for staff at all levels including residential staff. The Australian Parkinson’s Associations to work with educational institutions to develop training courses.
- Introduce interdisciplinary medical and allied health team management of PD clients and develop joint goal plans.
- Increased recognition of the impact of non-motor impairments on quality of life and the necessity to effectively manage these issues.
- Improve intervention outcomes with the use of evidenced based practice. Encourage research into and evaluation of, therapeutic interventions.
- Research and develop standardised assessment tools to be used by allied health professionals.
- Develop an interdisciplinary initial assessment tool to facilitate: the early identification of a range of issues, efficient referral on to other professionals and reduce unnecessary client assessment. This could be part of the role of the Key Worker.
- Employ an holistic and functional focus to therapeutic interventions and care management.
- Recognise that the clients’ perception of improved quality of life is the only relevant outcome measure of therapeutic intervention.
- Train clients and carers in the use of compensatory strategies to maintain function.
- Research and develop exercise program protocols to maintain physical and functional status – individualised and specific groups.
- Research and trial innovative interventions eg Voice Intensive Programs and Group Voice programs, Intensive Week Therapy programs.
• Recognise and utilise the potential of complementary therapies to improve function and quality of life eg. Tai Chi for Parkinson’s, Feldenkrais – Awareness through movement.

• Introduce personal patient-held, Care Pathway information/treatment files into treatment services as a means of increasing client involvement in the care process.

• Introduce Expert Patients programs, which focus on self-management skill development and client responsibility in the management of the treatment process.

• Provide education programs for carers to teach effective functional management skills to assist them to effectively help the person for whom they care, whilst maintaining their optimum independence.

• Ensure there are adequate support services available to carers for emotional support, to address respite needs and provide management advice to ease the burden of caring. Eg. PDNS, professionally manned help lines, carer groups.
4.5 Implementation

- Through my position as Vice-chair of the Parkinson’s Disease Association of South Australia I am able to advise in relation to strategic planning and implementing the recommendations in this report. The committee is supporting measures to lobby for the a PD Clinic in SA, for PDNS recognition and training, is planning education workshops and is applying for funding to address carer needs. Parkinson’s SA also has a role to play in lobbying government to prioritise the improvement of services for Parkinson’s.

- The Parkinson’s Professional Special Interest group will work with the Parkinson’s SA to facilitate education workshops. It will also review assessment tools with the aim of standardisation and the group is interested in using the large pool clients to evaluate intervention programs and develop protocols for therapy. The group is also to invite several influential Geriatricians to speak on the advantages of the holistic and interdisciplinary team approach to PD management.

- I have presented this report to the Continence Nurses Special Interest group, the Aged Care Interest Group, the Domiciliary Care Service and representatives of a large number of the metropolitan Therapy Services.

- Resthaven has requested a strategic planning meeting for Parkinson’s services within their Therapy Services and their residential care facilities to facilitate the development of protocols for standards of care management. This organisation is interested in supporting research and evaluation of specific projects in relation to the recommendations.

- The Repatriation General Hospital (SA), Rehabilitation Unit is planning to open a PD Clinic early in 2001 and has requested input into increasing staff knowledge and understanding of the benefits of the interdisciplinary Care Management Pathway.

- The Hampstead Rehabilitation Centre (Royal Adelaide Hospital), which is involved in research into exercise for older adults, is to investigate the development of exercise protocols for Parkinson’s exercise groups.

- I have responded to many individual requests from therapists for information in relation to the recommendations in the report, particularly in the areas of assessment, exercise and professional education.

- Summaries of the Fellowship have also been presented at Community Service Clubs and to consumer groups (Carers groups, The Young Onset Group and various current PD Exercise Groups) to raise awareness of the future directions for the management of Parkinson’s. This is an ongoing process because of continuing interest in the findings of the Fellowship.

- There has been media coverage, both print and radio to raise general community awareness.

- Copies of the Fellowship Report will be made available to the Australian Parkinson’s Associations, to the Rehabilitation Hospitals; the Government Health Department in SA and any other interested groups or individuals.
“This is not the end,
It is not even the beginning of the end,
But it is, perhaps,
The end of the beginning.”

- Sir Winston Churchill
References

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