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PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.
New Forest Branch

MY PARKINSON'S JOURNEY

A collaboration between the New Forest resources of the NHS and Parkinson's UK

1 Introduction

This handbook has been developed by patients living with Parkinson's and, if appropriate, their partners / carers, in conjunction with their NHS professionals. It reflects their experience and aims to assist with managing the relationship with the NHS and other professionals by creating a narrative record.
We are indebted to SOLENT NHS trust whose material inspired this handbook.

This version 1.0 of the handbook is a pilot, and if you've been given a paper copy, it's because you agreed to be part of that pilot and provide feedback when it comes to evaluate the success or otherwise. Please use the form in section 19 to record what you find helpful, areas that need enhancing or are missing, and, of course, if you find parts unhelpful that is equally important to record.

Parkinson's is a complex and progressive condition which affects each patient differently. Therefore, the treatment needs to be individual.Many people live with Parkinson's for decades and inevitably memory of what changed when and why fades. It is therefore important that patients keep a record for their own purposes in addition to NHS records. For example, the prescription record will show the medication being prescribed through time but will not show WHY changes were made. Many PD medications have side effects which affect some more than others. Knowing that it was these side effects which caused the change in medication can be important later in life.

As time and the condition progresses there are changes to symptoms. The section Clinical Review.is intended to help the patient prepare for the important, albeit short, meetings with the specialist adviser and ensure that key concerns are discussed.

PLEASE BRING THIS HANDBOOK WITH YOU TO THE REVIEW

Ask the consultant or nurse specialist to update the treatment record

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2 Index

3 About Me

Name	
Date of Birth	
Address	
Post Code	
Home Phone Number	
Mobile Phone Number	
NHS Number	
Hospital Number	

3.1 Next of Kin / Emergency Contacts

Name		
Address		
Post Code		
Home Phone Number		
Mobile Phone Number		

Name		
Address		
Post Code		
Home Phone Number		
Mobile Phone Number		

Name		
Address		
Post Code		
Home Phone Number		
Mobile Phone Number		

3.2 Key Contacts

Role	Name	Phone
Parkinson’s Nursing Team		0300 0032186 01590 663446
GP		
Consultant		
Parkinson’s Adviser	Rosemary Smith	0344 225 3678
Adult Services (Hampshire Social Service)		0300 555 1386

4 My Diagnosis

PD Type	
Date of diagnosis	
Diagnosing Doctor	
Other conditions	
Allergies	

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5 Current Medication Plan

Use the following template to document your medication plan, while this may not seem to be necessary while your medication plan is simple, it's a good practice to get into for when it becomes more complex. A credit card sized folding version is available from Parkinson's UK, by calling 0333 0030 523 and requesting M001

It also serves at least two other purposes:

- Communication with your consultant or specialist nurse (though don't be surprised if they make their own notes!)
- If you are taken in to hospital or someone who is unfamiliar with your plan needs to assist you with your medication

Enter the medication name in the top row, followed by the dose. Enter the time taken in the left hand column and the number of tablets at the intersection of the medicine name and the time (normally 1)

Apomorphine pump	
My pump is administered by	
Telephone Number	
Flow Rate	
Start Time	
Stop Time	

DBS	
I have a DBS Unit. The serial number is:	
My DBS Nurse is	
Telephone	
My DBS Specialist is	
Telephone	

APO-go Pen and APO-go syringe	
I use a Pen / Syringe	Delete as appropriate
I use the following type of needle	
I use the following type of syringe	

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Current Medication Plan

Name :………….

Date : __/__/__

Medication Name								
Time / Dose								

Notes :

Name :…………..

Date : __/__/__

Medication Name								
Time / Dose								

Notes:

6 Medication History

Your prescription history will detail the changes in your medication, however it may not be easy to find why medications were changed or stopped.

If you take part in research programmes it is likely that you will be asked about your medication history. While that is simple initially, as it becomes more complex and new drugs arrive, then remembering all of the different drugs and why you changed or stopped taking them becomes impossible.

Two different forms are provided, the first is for your regular medication for Parkinson’s motor symptoms, such as Madopar, Sinemet etc. on which you can track your dosage history. The second is for any other drugs which you take, maybe to alleviate non motor symptoms or for another condition.

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Medication History PD specific – variable dose – Co-careldopa, co-beneldopa, stalevo

Name :		Drug :	Co-careldopa 100/25
Date Started :	1/10/2017	Date Finished :	
Reason for start :	Slow gait / poor balance	Reason for finish	

1/10/2017						
Time	0700	10:30	14:00	17:30	21:00	
Dose	2	1 1/2	1 1/2	2	1 1/2	
1/5/2018						
Dose	1 1/2	1 1/2	1 1/2	1 1/2	1 1/2	Entacapone effective

Name :		Drug :	Entacapone 200mg
Date Started :	1/4/2018	Date Finished :	
Reason for start :	On / off symptoms	Reason for finish	

1/4/2018						
Time	0700	10:30	14:00	17:30	21:00	
Dose	1	1	1	1	1	
1/5/2018						

Medication History - All previous and current

Medication	Dose	Date Started	Date Stopped/ changed	Reasons

Medication	Dose	Date Started	Date Stopped/ changed	Reasons

7 Keeping a Diary

Many people find keeping a diary a useful method of keeping track of their symptoms over time.

In addition, if you take part in research projects, then you're likely to get asked questions about when symptoms first appeared and / or when you started or stopped taking medication. Without some form of written record, these dates all get lost in the mists of time.

There is no right or wrong format, use what suits you and at a frequency which suits your lifestyle and symptoms. In the early stages, this can be very light, but as things become more complex a more detailed and more frequent entry may be appropriate.

Parkinson's UK provides a leaflet called Monitoring Your Parkinson's which is available from their website (https://www.parkinsons.org.uk/information-and-support/monitoring-your-parkinsons) or through your local Parkinson's adviser.

7.1 Parkinson's symptoms

The Parkinson's Foundation has a very detailed worksheet which could be useful for tracking particular symptoms over a short period of time. It can be downloaded from their website (https://www.parkinson.org/pd-library/fact-sheets/symptoms-diary)

It is not expected that a diary would be kept for most symptoms all the time - many people will not need to use this at all. However, occasionally, after discussion in the clinic, it might be suggested that a diary for a specific symptom would be useful in order to decide on appropriate treatment and these pages might be a helpful format.

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Month/ Year:

Date	Morning	Afternoon	Evening	Night
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				

Date	Morning	Afternoon	Evening	Night
16				
17				
18				
19				
20				
21				
22				
23				
24				
25				
26				
27				
28				
29				
30				
31				

7.2 Falls and stumbles (or near misses “e.g. walking on ice”)

Date	How did you fall?	Any injury?	Any obvious cause	Walking aid in use? What?

Date	How did you fall?	Any injury?	Any obvious cause	Walking aid in use? What?

8 Clinical Review

To prepare for your meeting with the specialist Parkinson's team in clinic , you might find it helpful to use the following preparation sheet.

The movement or motor symptoms of Parkinson's (tremor, shaking, stiffness and slowness) are well known. However, other problems can sometimes occur as part of the condition or its treatment. It is important that the team knows about these, particularly if they are troublesome for you. A range of possible problems is listed below to remind you if there is anything you wanted to bring up. Many people do not have any of these symptoms however, so don't worry if you aren't ticking any boxes!.

Prior to each clinical review, complete a new copy of the form and decide which are the top 2 or 3 symptoms that you wish to discuss. Retain the forms in this section to track how your situation progresses. It is anticipated that you will be sent a copy of this form with your clinic appointment letter but occasionally if your appointment has been arranged by phone or at short notice, its helpful to use one of these spares.

PLEASE BRING THIS HANDBOOK WITH YOU TO THE REVIEW

If you are not confident to do it yourself, ask the doctor or nurse specialist to update the treatment record

8.1 Your partner / carer / family as an observer

Clinical reviews and doctors appointments are inevitably time-constrained and concentrated. It is therefore useful if you can take someone close to you to any appointment for two reasons:

- As an independent observer of your symptoms. Things change relatively slowly, so you may not recognise the level or significance of changes. Having someone who is close to you who can monitor and quantify changes is helpful.
- To ensure you capture all of the information given to you. It is very easy when being told something, to consider the implications of what you've just been told and in doing so, miss the next piece of information.

8.2 Activities of daily living

Activities of daily living is a term used in healthcare to refer to people's daily self care activities. It is not specific to Parkinson's.

The basic activities can be considered those that you would undertake on getting out of bed in the morning and going out. The instrumental activities are more complex things like looking after the house and money. The lists vary, but the following table is typical and is included for information. Some people find it a useful way to describe how well they manage life to health professionals or care workers.

Function	No assistance needed	Need some assistance	Complete assistance needed
Basic Activities of Daily Living			
Bathing			
Climbing stairs			
Dressing			
Eating			
Grooming - hair, nails, teeth etc			
Toileting			
Transferring bed/chair			
Walking			
Instrumental Activities of Daily Living			
Cooking			
Doing housework			
Doing laundry			
Managing finances			
Managing medication			
Shopping			
Using the phone			
Using transportation			

What would you like to focus on?

From reviewing the questionnaire you may have highlighted some areas that you would like to focus on at your next clinic appointment. Please consider writing down the 3 most important things that you would like to discuss. You will not be restricted to only talking about these, but may find it useful as a starting point.

1 ____

____

____

2 ____

____

____

3 ____

____

____

Thinking ahead

You may wish to consider your plans and wishes for the future. This might include thinking about what aspects of your life, such as relationships, hobbies and beliefs, as well as health and care needs, are important to you.

Some questions that can be useful to think about are:

1. What is important to you now? What makes you happy?
2. What elements/aspects of care are important to you?
3. Is there anything that you worry about, or fear happening in the future?

Having done this, you may want to make a records of your thoughts so others know and can take appropriate action in future; There are a number of ways to do this. Any member of the PD team who you see in clinic would be happy to discuss this with you – or you may prefer to speak to the PD specialist nurse and team or even the care navigator at your local GP surgery.

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Patient with Parkinson's Self Review Questionnaire

My next appointment is…

………………………………………………

………………………………………………

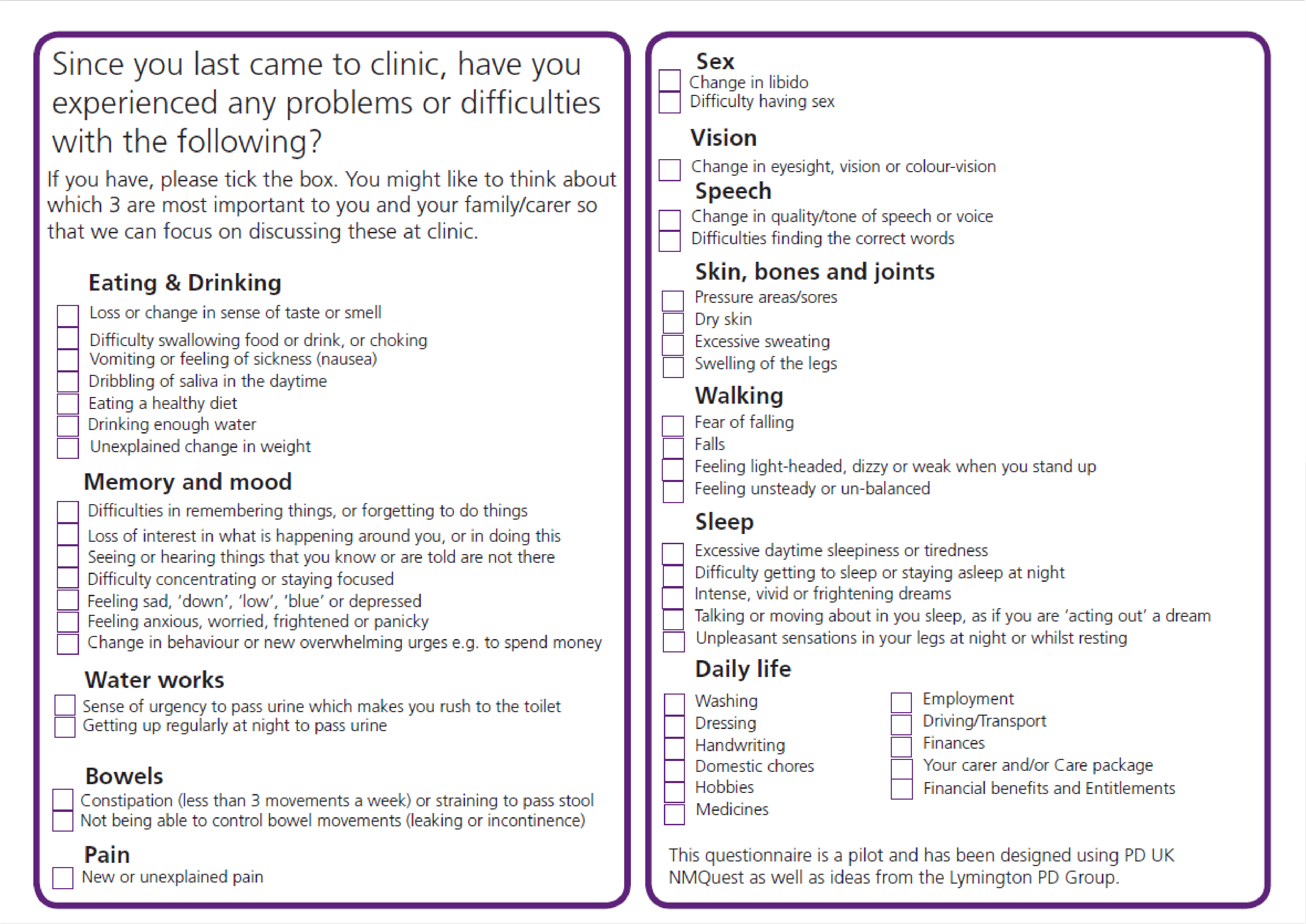
………………………………………………

Lymington PD contact details

Tel: 0300 003 2186 (answer phone)

Tel: 01590 663446 (Mon, Wed & Thur 0900-1500hrs)

Email: shft.parkinsonsdisease@nhs.net



Since you last came to clinic, have you experienced any problems or difficulties with the following?

If you have, please tick the box. You might like to think about which 3 are most important to you and your family/carer so that we can focus on discussing these at clinic.

Eating & Drinking

☐ Loss or change in sense of taste or smell
☐ Difficulty swallowing food or drink, or choking
☐ Vomiting or feeling of sickness (nausea)
☐ Dribbling of saliva in the daytime
☐ Eating a healthy diet
☐ Drinking enough water
☐ Unexplained change in weight

Memory and mood

☐ Difficulties in remembering things, or forgetting to do things
☐ Loss of interest in what is happening around you, or in doing this
☐ Seeing or hearing things that you know or are told are not there
☐ Difficulty concentrating or staying focused
☐ Feeling sad, 'down', 'low', 'blue' or depressed
☐ Feeling anxious, worried, frightened or panicky
☐ Change in behaviour or new overwhelming urges e.g. to spend money

Water works

☐ Sense of urgency to pass urine which makes you rush to the toilet
☐ Getting up regularly at night to pass urine

Bowels

☐ Constipation (less than 3 movements a week) or straining to pass stool
☐ Not being able to control bowel movements (leaking or incontinence)

Pain

☐ New or unexplained pain

Sex

☐ Change in libido
☐ Difficulty having sex

Vision

☐ Change in eyesight, vision or colour-vision

Speech

☐ Change in quality/tone of speech or voice
☐ Difficulties finding the correct words

Skin, bones and joints

☐ Pressure areas/sores
☐ Dry skin
☐ Excessive sweating
☐ Swelling of the legs

Walking

☐ Fear of falling
☐ Falls
☐ Feeling light-headed, dizzy or weak when you stand up
☐ Feeling unsteady or un-balanced

Sleep

☐ Excessive daytime sleepiness or tiredness
☐ Difficulty getting to sleep or staying asleep at night
☐ Intense, vivid or frightening dreams
☐ Talking or moving about in you sleep, as if you are 'acting out' a dream
☐ Unpleasant sensations in your legs at night or whilst resting

Daily life

☐ Washing
☐ Dressing
☐ Handwriting
☐ Domestic chores
☐ Hobbies
☐ Medicines
☐ Employment
☐ Driving/Transport
☐ Finances
☐ Your carer and/or Care package
☐ Financial benefits and Entitlements

This questionnaire is a pilot and has been designed using PD UK NMQuest as well as ideas from the Lymington PD Group.

Clinic Follow up letters

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10 Self Help

10.1 Base Case Checks

Many symptoms are aggravated by other infections or not taking medication as prescribed, so base case checks are:

- Be sure that you are taking the correct dose at the correct time
- If your medication has changed and your symptoms deteriorate contact your Parkinson’s nurse
- If you have a temperature, fever, fatigue, loss of appetite, aches or pains then these may indicate an underlying infection as the cause of the deterioration and you should contact your GP

10.2 Action plans

There are many areas where you may be able to reduce symptoms or solve problems without reference to your PD Specialist or consultant.

Non Motor Symptom	**Read Action plan**	**Further Information**	**Ref No**
Eating & Drinking			
Loss or change in sense of taste or smell			
Difficulty swallowing food or drink, or choking		Eating, swallowing and saliva control in Parkinson’s	FS22
Vomiting or feeling of sickness (nausea)			
Dribbling of saliva in the daytime		Eating, swallowing and saliva control in Parkinson’s	FS22
Eating a healthy diet		Diet and Parkinson’s	B065
Drinking enough water	10.2.11 Urinary problems and hydration		
Unexplained change in weight			
Memory and mood			
Difficulties in remembering things, or forgetting to things		Mild memory and thinking problems in Parkinson’s	FS95
Loss of interest in what is happening around you, or in doing this	10.2.9 Depression 10.2.4 Mental health	Depression and Parkinson’s	FS56
Seeing or hearing things that you know or are told are not there	10.2.10 Hallucinations and delusions	Hallucinations and delusions in Parkinson’s	FS11
Difficulty concentrating or staying focused	10.2.9 Depression	Mild memory and thinking problems in Parkinson’s	FS95
Feeling sad, 'down', 'blue' or depressed	10.2.9 Depression	Depression and Parkinson’s	FS56
Feeling anxious, worried, frightened or panicky		Anxiety and Parkinson’s	FS96

Non Motor Symptom	**Read Action plan**	**Further Information**	**Ref No**
Change in behaviour or new overwhelming urges e.g. to spend money		Impulsive and compulsive behaviour in Parkinson's	FS77
Water works			
Sense of urgency to pass urine which makes you rush to the toilet	10.2.11 Urinary problems and hydration	Looking after your bladder and bowels when you have Parkinson's	B060
Getting up regularly at night to pass urine	10.2.11 Urinary problems and hydration	Looking after your bladder and bowels when you have Parkinson's	B060
Bowels			
Constipation (less than 3 movements a week) or straining to pass stool	10.2.2 Constipation	Looking after your bladder and bowels when you have Parkinson's	B060
Not being able to control bowel movement (leaking or incontinence)		Looking after your bladder and bowels when you have Parkinson's	B060
Pain			
New or unexplained pain	10.2.7 Pain	Pain in Parkinson's	FS37
Sex			
Change in libido		Intimate relationships and Parkinson's	B034
Difficulty having sex		Intimate relationships and Parkinson's	B034
Vision			
Change in eyesight, vision or colour-vision		Eyes and Parkinson's	FS27
Speech			
Change in quality/tone of speech or voice		Speech and language therapy and Parkinson's	FS07
Difficulty in finding the correct words		Mild memory and thinking problems in Parkinson's	FS95
Skin, bones and joints			
Pressure areas/sores			
Dry skin			
Excessive sweating		Skin and sweating problems in Parkinson's	FS40
Swelling of the legs			

Walking			
Fear of falling	10.2.5 Mobility		
Falls		Falls and Parkinson's	FS39
Feeling light-headed, dizzy or weak when you stand up		Falls and Parkinson's	FS39
Feeling unsteady or un-balanced	10.2.5 Mobility		
Sleep			
Excessive daytime sleepiness or tiredness	10.2.3 Fatigue and Sleepiness	Sleep and night-time problems in Parkinson’s	B070
Difficulty getting to sleep or staying asleep at night	10.2.3 Fatigue and Sleepiness	Sleep and night-time problems in Parkinson’s	B070
Intense, vivid or frightening dreams	10.2.10 Hallucinations and delusions	Hallucinations and delusions in Parkinson’s	FS11
Talking or moving about in you sleep, if you are 'acting out' a dream		REM behavioural sleep disorder	FS83
Unpleasant sensations in your legs at night or whilst resting		Muscle cramps and dystonia Restless legs syndrome and Parkinson’s	FS43
Daily life			
Washing		Tips and Hints Living with Parkinson’s Taking Control when you have Parkinson’s	B011 B077 B503
Dressing			
Domestic Chores			
Hobbies			
Medicines			
Handwriting		Communications	FS06
Employment		Work and Parkinson’s	B103
Driving/Transport		Driving and Parkinson’s	B064
Finances			
Your carer and/or care package		The Carer’s Guide	B071
Financial Benefits and entitlements		Multiple leaflets, one per benefit	WB 1 – 21

10.2.1 Action plan index

10.2.2 Action Plan – Constipation

Aim: To reduce and relieve complications caused by constipation

	Symptoms		Action
🟢	Constipation is a common problem for most people with Parkinson's. It can cause a worsening of your symptoms as the medication doesn't reach the area where it is absorbed. This can lead to increased muscle rigidity	→	Eat a healthy balanced diet with at least five portions of fruit and vegetables per day. Sometimes dried fruit such as dried apricots (taken as a late night snack whilst watching TV with a glass of water) can be a useful addition to other diet. Keep hydrated by drinking at least 10 cups of fluid per day Exercise daily, such as going for a walk Take your laxatives as prescribed Be aware that some pain killers, such as Codeine or Co-Dydramol, make you more prone to constipation. Laxatives such as Laxido and Movicol are available with or without a prescription from your pharmacy
Worsening Symptoms 🟡	If your stools become more difficult to pass or you have not had a bowel movement for three days	→	Increase your fluid intake to at least 12 cups per day Increase your activity level Check you have been taking your laxatives as prescribed Increase dose of laxative within agreed limits- if stool is very soft but still difficult to pass, you may need to take a stimulant laxative such as Senokot. These can be purchased over the counter. Take 2 at night as well as Laxido and Movicol. Contact your GP or Parkinson's Nurse for advice or call 111
Severe Symptoms 🟠	If you have not had a bowel movement for 5 days or you have abdominal pain	→	Contact your GP
Danger Signs 🔴	Usually, if you have been vigilant about bowel using the steps above, There should be no need to call an ambulance or to visit A & E for constipation unless you get bleeding through the rectum or severe abdominal pain .,	→	

10.2.3 Action Plan – Fatigue and sleepiness

Aim: To manage fatigue and sleepiness

	Symptoms		**Action**
🟢	No fatigue or normal levels of fatigue that are manageable with regular pacing and resting	→	Continue with usual routine of daily living Continue with current fatigue management interventions
Worsening Symptoms 🟡	Increased level of fatigue, that is coming on gradually, but is beginning to impact on functioning, needing more rest periods and / or sleeping more during the day	→	Keep a note of fatigue levels and symptoms - for example does it occur at any particular time of day or after any particular activity. This can be discussed non urgently with the PD nurse or at your next clinic appointment. If you are drowsy during the day and or fall asleep at unexpected times – for example during meals this may need an adjustment to your medication – contact your PD nurse.
Severe Symptoms 🟠	Sudden onset of fatigue that impacts on all functioning. Unable to complete any activities of daily living Falling asleep in the middle of a meal or during driving	→	Contact GP to investigate cause such as infection or other metabolic causes. Sudden onset drowsiness needs review of medication. If you suffer from this you should not drive until it is sorted out. Contact Parkinson's Nurse for further advice.
Danger Signs 🔴	There should be no cause to call an ambulance or to visit A&E for symptoms of fatigue.	→	

10.2.4 Action Plan – Mental Health

Aim: To support and monitor any deterioration in cognitive processes

	Symptoms		**Action**
🟢	It is usual for people to experience some age related memory loss. It is also usual for people with living with Parkinson’s to experience mild hallucinations or delusions (see separate action plan)	➡	Using strategies such as writing lists and leaving prompts close to hand can be useful when experiencing some memory loss. If you have any concerns about your memory or cognitive thought processes or you have started to have mild hallucinations – report this at the next clinic or contact your Parkinson's nurse or consultant
Worsening Symptoms 🟡	If your memory loss becomes problematic or If you are having difficulty with thought processing (Parkinson’s can affect your ability to sequence and execute tasks) or If you are noticing changes in your behaviour or have become low in mood	➡	Check that you are taking your medication correctly, i.e. the correct dose at the correct time. If there has been a recent change to your medication contact your Parkinson’s Nurse. If you are known to the mental health team, contact them, otherwise contact your Parkinson’s nurse or consultant.
Severe Symptoms 🟠	If you have a sudden and significant deterioration in your memory, a sudden change in your cognitive thought processing or a sudden increase in confusion	➡	You may have a condition called delirium- the causes of this are many but include infection, constipation, dehydration and medication as well as some metabolic problems. Contact your GP or the Out of Hours service for advice (111).
Danger Signs 🔴	If you feel that your symptoms are leading to suicidal or aggressive thoughts thus posing a risk to you or to others	➡	Contact your GP, or the Out of Hours Service (111) for advice

10.2.5 Action Plan – Mobility

Aim: To maintain your mobility and balance

	Symptoms		**Action**
🟢	Walking your normal distance with the appropriate aid or level of assistance if required You do not fall, or if you do, then there is an obvious reason, such as you tripped over an object	→	Continue to mobilise. It is important that you mobilise regularly. Consider going to an exercise class, dancing, yoga, Tai chi, all of which will help your longer term mobility Remove all trip hazards
Worsening Symptoms 🟡	Walking is more effort. You feel unsteady or you feel at risk of falling You have fallen, but appear OK with no obvious injuries You frequently fall, but do not hurt yourself	→	Ensure you are using your walking aid correctly Check your medication is being taken correctly Check for signs of underlying infection such as a temperature, fatigue, or loss of appetite Update your Falls Diary Contact your GP for review and referral for further assessment of walking and balance by the community therapy team.
Severe Symptoms 🟠	If you are struggling with your mobility so that you are unable to walk the distances required for daily living in your house or to transfer safely and this has changed in the recent past	→	Contact the PD Nurse or your GP for a full assessment They may refer you to the community therapy team for advice about equipment and exercise.
Danger Signs 🔴	Fallen over and hurt yourself or unable to get up	→	Your carer / partner should call an ambulance or contact the emergency doctor. If you live alone, use the Careline alarm to summon assistance. If you don't have a Careline alarm, try to reach the phone or attract attention from someone passing Update your Falls Diary

10.2.6 Action Plan – Motor Symptoms

Aim: Reduce and relieve motor symptoms of PD

	Symptoms		Action
🟢	Muscle rigidity, stiffness, slowness of movement, and difficulty initiating movement are all symptoms of Parkinson’s Most people will find that it is usual to have some days when these symptoms are more troublesome than usual	→	Occasional days when symptoms are worse is usual and no action needs to be taken.
Worsening Symptoms 🟡	If these symptoms occur each day	→	Check medication is being taken correctly If new medication has been introduced or the dose of existing medication changed, contact your Parkinson’s Nurse Keep a note of symptoms for 4 -5 days and then contact your Parkinson’s Nurse
Severe Symptoms 🟠	Sudden deterioration in these symptoms accompanied by feeling unwell	→	You need to be checked for any signs of an underlying illness contact your GP during surgery hours or 111 at weekend during the day. . If no underlying illness is found, contact your Parkinson’s Nurse
Danger Signs 🔴	There should be no cause to call an ambulance or to visit A&E for these symptoms unless they have resulted in a fall or other injury.	→	If you have injured yourself, call 999 for an ambulance.

10.2.7 Action Plan – Pain

Aim: Manage pain

	Symptoms		Action
🟢	You are experiencing no pain or the same level of pain you usually have.	➡	Continue with normal levels of activity and exercise programmes. Occasional days when symptoms are slightly worse is usual for people with a neurological condition and no action needs to be taken.
Worsening Symptoms 🟡	If your pain level increases for more than 2-3 days or You experience new pain	➡	Have you done anything that may have exacerbated your pain (e.g. increased walking, driving, standing), if so return to normal activity levels Check medication being taken correctly Has any new medication been introduced? If so contact your Parkinson’s nurse or or pharmacist? Keep a diary of your symptoms and then contact either either your GP or Parkinson’s nurse for further advice
Severe Symptoms 🟠	Sudden severe pain with no known reason .	➡	Take simple pain killers such as paracetamol and rest with a hot drink for a while. If it doesn’t settle, then call your GP or 111 for advice.
Danger Signs 🔴	Sudden chest pain Sudden shortness of breath Sudden abdominal pain which is so bad you can’t take a breath	➡	Dial 999 for an ambulance

10.2.8 Action Plan – Tremor

Aim: To reduce disability due to tremor when present

	Symptoms		**Action**
🟢	70% of people living with Parkinson's will have a tremor. It is usual for this to worsen with anxiety.	→	Deliberate relaxation exercises such as following a relaxation tape or mindful breathing. Avoid stimulants such as caffeinated drinks, tea, coffee, alcohol and cigarettes.
Worsening Symptoms 🟡	If tremor gets worse	→	Check medication taken correctly If new medication has been introduced or the dose of existing medication changed, contact your Parkinson's Nurse Remember that tremor is the most difficult symptom to treat with medication so it won't necessarily improve straight away with medication change. Contact Integrated Community team at the Becton Centre 01425 627802 (for Lymington and New Milton) or 02380 428488 (for Hythe, Totton and Lyndhurst) for assessment and advice in relation to activities of daily living and /or Parkinson's nurse for full PD assessment
Severe Symptoms 🟠	If a sudden degeneration in tremor	→	Check for signs of underlying infection such as a temperature, fatigue, or loss of appetite, if present, contact your GP If no sign of infection present contact your Parkinson's nurse
Danger Signs 🔴	A tremor is not dangerous and there should be no need to call an ambulance.	→	If you have any doubts call your GP or 111

10.2.9 Action Plan – Depression

Aim: To support and monitor any deterioration in mood

	Symptoms		**Action**
🟢	It is usual for people to experience low mood on some days	→	Having a positive attitude and maintaining social connections can help you cope with the day to day challenges of Parkinson's
Worsening Symptoms 🟡	If you are regularly losing interest in doing things or going out If you have difficulty concentrating If you are experiencing feelings of low mood most days Loss of appetite and weight loss	→	Check medication taken correctly If new medication has been introduced or the dose of existing medication changed, contact your Parkinson's Nurse If you are known to the mental health team, contact them. If not contact your Parkinson's Nurse, Consultant, or GP
Severe Symptoms 🟠	If you have feelings of hopelessness every day If you are having trouble sleeping, such as waking in the early hours	→	Contact your Parkinson's Nurse, Consultant, Mental Health Team or GP
Danger Signs 🔴	If you feel that your low mood is causing suicidal thoughts or aggression which is posing a risk to you or to others	→	Contact your GP or the out of hours service (111).

10.2.10 Action Plan – Hallucinations and delusions

Aim: To minimise the impact of Hallucinations and Delusions

	Symptoms		Action
🟢	It is usual for some people with living with Parkinson's to experience mild hallucinations Some Parkinson's medications aggravate this and your medication plan may need to be changed.	➡	If you have started to have mild hallucinations or delusions contact your Parkinson's nurse or consultant
Worsening Symptoms 🟡	If your hallucinations or delusions have become troubled or If you are noticing changes in your behaviour	➡	Check medication taken correctly If new medication has been introduced or the dose of existing medication changed, contact your Parkinson's Nurse Check for signs of underlying infection such as a temperature, fatigue, or loss of appetite, if present, contact your GP If you are known to the mental health team, contact them. If not contact your Parkinson's Nurse, Consultant, or GP
Severe Symptoms 🟠	If you have a sudden increase in your hallucinations or delusions or are becoming confused	➡	Contact your Parkinson's Nurse, Consultant, or GP
Danger Signs 🔴	If you have a sudden increase in your confusion or hallucinations or are having frightening thoughts or ideas	➡	Contact your GP or the Out of Hours Service (111) for advice

10.2.11 Action Plan – Urinary problems / hydration

Aim: To Support comfort and continence

	Symptoms		Action
🟢	Many people with Parkinson’s disease experience a more frequent need to pass urine and can get a degree of urgency - so that they have to get to the toilet urgently. It is common for this to be more difficult if the medication level is low . Many people even without Parkinson’s experience more urinary frequency with larger volumes overnight than during the day.	→	Report any symptoms you do get at the regular review with the PD specialists. You might want to keep a 3 day bladder diary if its difficult to recall the pattern of your bladder emptying. In men, it is particularly important to report difficulty in passing urine such as a poor or weak stream or dribbling at the end of passing water when you think you have finished – as this might be due to an enlarged prostate and nothing to do with Parkinson’s.
Worsening Symptoms 🟡	If it starts to be painful to pass urine(such as burning or stinging) If there is blood in the water If there is no pain but increasing frequency and even incontinence	→	Report to the GP – you may be asked to provide a specimen. Depending on the symptoms s/he may arrange for you to see another specialist. Contact the PD nurse- who may refer you on for a continence assessment. Remember incontinence pads are available to buy in all pharmacies and in many supermarkets. In some cases the NHS will supply pads, but these are rarely enough to avoid having to supply some of your own
Severe Symptoms 🟠	If incontinence of urine suddenly becomes worse ie flooding or severe urgency and frequency with or without pain (but no fever or chills)	→	Consider whether you might be very constipated - see action plan for this if so. Make a non urgent appointment to see the GP for assessment. If increasing pain - Contact your GP or 111 out of hours. Remember incontinence pads are available to buy in all pharmacies and in many supermarkets. In some cases the NHS will supply pads, but these are rarely enough to avoid having to supply some of your own
Danger Signs 🔴	Being unable to pass urine at all Having severe pain or blood in the urine and having a temperature, fever or chills	→	Call 111 or contact your own doctor for urgent assessment. However, if you already have a urinary or suprapubic catheter in place, call the community nurses on 01425 627802(for Lymington and New Milton) or 02380 428488 (for Hythe, Totton and Lyndhurst).

11 Sources of help, support and information

11.1 Parkinson's UK

Parkinson's UK, (www.parkinsons.org.uk or 0808 800 0303) has an extensive set of advice about all aspects of Parkinson's in both printed and electronic format. The local adviser is there to help you, contact details on the loose flyer included. The website also has a forum for asking questions of others with PD.

11.2 Local Branch Website

The local branch website has details of the local branch activities and local information about support services and much else (https://www.parkinsonsnewforest.org)

11.3 NHS

The NHS website (https://www.nhs.uk/conditions/parkinsons-disease) has information around the medical aspects of Parkinson's, and where it is outside the NHS scope, links to other services

11.4 Hampshire County Council

HCC provides a great deal of information through its support website (https://www.connecttosupporthampshire.org.uk/home) and matching booklet A guide to Better Care and Support which can be downloaded from the website or obtained by post by calling Adult Services on 0300 555 1386

11.5 Helpful Books

Parkinson's – at your fingertips guide, Oxtoby / McCall / Williams

Everything you need to know about Parkinson's Disease, Lianna Marie

The Selfish Pigs Guide to Caring, Hugh Marriott

11.6 Local Parkinson's UK Activities

11.6.1 Branch meeting

The local branch of Parkinson's UK meets on the 3rd Thursday of every month at Boldre War Memorial Hall at 2pm. The programme is usually a speaker followed by tea and biscuits and a chance to chat. After tea, there may be short presentations on local services or research activities being undertaken at Southampton. It's an informal and friendly group of people suffering from or affected by PD.

For more information call the Branch Chairman listed on loose flyer enclosed.

11.6.2 Pub Lunches

The branch runs a pub lunch on the 4th Thursday of alternate months check the website https://www.parkinsonsnewforest.org/index.php/about-us/forthcoming-events for details.

11.6.3 Coffee Mornings

Informal drop in coffee mornings occur on 2nd Monday of each month, check the website https://www.parkinsonsnewforest.org/index.php/about-us/forthcoming-events for details.

11.6.4 Exercise Class

Lymington Area Parkinson’s Support (LAPS) runs an Extend exercise class on Tuesdays at Boldre War Memorial Hall at 10:30 am. It is suitable for all capabilities and partners.

11.6.5 Local exercise centres

The Hampshire County Council website lists 75 different activities / centres around the New Forest. Add to this all the privately run opportunities and you have a huge choice. In addition to the usual gym based classes, there’s sailing, riding and many more.

The five centres run by NFDC (Lymington, Applemore, Ringwood, Totton and New Milton are supplemented by Brockenhurst College and many other organisations.

See 12.2.1 and 12.2.2 for more information on specific exercises

12 Maintaining quality of life

The diagnosis of Parkinson’s can be devastating for the PwP and for those around them. Shock, fear and a host of other emotions dominate. It’s natural to feel that life has suddenly changed but actually you’re the same person with the same capabilities on the day after diagnosis as you were the day before. It certainly doesn’t feel that way!

12.1 Maintain your social contacts outside of Parkinson’s

Parkinson’s can dominate life if you let it, but it doesn’t have to. The more you can continue with your routines and friendships the better. As symptoms develop, you may need to adapt to them, never give in!

12.2 Minimising the impact of Parkinson’s on everyday life

We are often told **“use it or lose it”** and while we may think that it is an old wives tale that is not the case for Parkinson’s.

Parkinson’s UK says (Exercise):

> Doing 2.5 hours of exercise a week can
> slow the progression of your symptoms.

There is a wide body of scientific evidence that “using it”, be it our voice or mind or muscles helps to maintain all of these functions in a better condition than if they are not used. These studies are all relatively short term. It is too expensive and difficult to track enough participants over multiple years to conduct long term studies. However there is evidence from similar studies in mice that there are long term benefits of “using it”

For people who have not customarily exercised regularly, this is a significant change in lifestyle, but the benefits outweigh the inconvenience, particularly as it is likely to maintain these functions into later life.

12.2.1 Physical exercise

The NHS recommendation is at least 2 ½ hours of exercise per week, at a level which increases your heart rate and makes you perspire slightly. This exercise can take many forms, specific Parkinson’s exercise classes, dancing, Tai Chi or Yoga have all been shown to be beneficial. Each has different benefits, for example Tai Chi and Yoga promote balance whereas dance improves gait function and balance. The NICE guidelines recommend Alexander Technique for those with balance or motor function problems. The PD Warrior course is also well respected.

12.2.2 Parkinson’s UK Exercise Framework

The Parkinson’s UK Exercise framework, included on the next two pages, is based on extensive review of scientific studies. Both the framework and scientific references can be found on the Parkinson’s UK website.
https://www.parkinsons.org.uk/information-and-support/parkinsons-exercise-framework

12.2.3 Voice

Singing uses the same muscles as swallowing and breathing control, which can both be affected by Parkinson’s. Singing exercises these muscles and improves the muscle activity and strengthens the muscles.

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Parkinson's exercise framework

Key messages for professionals to give the people they support

	Investing in exercise from diagnosis onwards	Staying active	Managing complex (physical) challenges
Focus	Emerging evidence suggests that increasing exercise to 2.5 hours a week can slow the progression of Parkinson's symptoms, so: • seek referral to an informed professional to discuss exercise and its benefits, the individual's physical state and motivation • exposure to an exercise-focused lifestyle (that is sociable and fun), using family, friends or Parkinson's networks, supports regular exercise behaviour • if symptoms are mild, this is the optimal time to improve physical condition to remain well, prevent inactivity and the complications of sedentary behaviour (weight gain, heart disease and metabolic disorders such as diabetes and osteoporosis)	Keeping moving is important for people with Parkinson's, so: • stay as (or more) active than at diagnosis and increase exercise targeting Parkinson's-specific issues such as balance and doing two things at once (dual tasking) • continue to keep the progression of symptoms to a minimum by exercising both the body and the mind (especially for memory, attention, and learning) • use the positive effects of exercise to better manage non-motor symptoms such as mood and sleep	Movement, ability and motivation change over time, so: • pay attention to specific physical functions that focus on daily activities such as getting up out of a chair, turning or walking safely • continue to maintain general fitness for physical wellbeing, finding ways to make sure this is kept up • prevent discomfort related to postural changes
Exercise style (bearing in mind fitness and any barriers to exercise such as travel or fatigue)	Target postural control, balance, large movement (including twisting) and coordination through: • moderate and vigorous intensity exercise to get the best performance from the body. Best done 5 x week in 30 minute bouts (can be built over time) • progressive resistance exercise to build muscle strength and power. Best results if done 2 x week • Parkinson's-specific exercise prescribed by health professionals such as dual-tasking and stretching for flexibility. Best results if done 2 x week (Evidence from animal models that vigorous intensity exercise may have neuroprotective effects is in its infancy with humans, so more research is needed.)	Target flexibility (dynamic stretching), plus slower exercise to control postural muscles for balance through: • maintaining effortful exercise that pushes people according to their fitness levels • continuing resistance exercises • increasing balance exercises • increasing postural exercises • Parkinson's-specific review by health professionals	Target better movement through: • functional exercise (chair-based with the use of resistance bands) • supervised classes with a professional reviewing safety to perform exercise • home programmes to stay moving, avoid sedentary behaviour, reduce flexed position and the secondary effects of being less mobile

Parkinson's exercise framework

Examples of exercise styles to focus on

	Investing in exercise from diagnosis onwards	Staying active	Managing complex (physical) challenges
Examples	• Sport: racket sport, cycling, jogging, running and swimming • Leisure centre and other classes: aerobics, vigorous intensity training (such as boot camps with high level balance work), Nordic walking • Home DVDs or high intensity exergaming • Parkinson's-specific exercise such as PD Warrior, boxing training classes, the Parkinson's Wellness Recovery (PWR!) programme, some exercise classes run by the Parkinson's UK network	• Golf, bowling, (paired) dance, health walks, swimming • Flexibility with strength: tai chi, Pilates and yoga • Specific classes for people with Parkinson's such as LSVT BIG and balance and walking classes (run by the Parkinson's UK network)	• Specific classes for people with mobility and balance challenges, especially dance • Pedal exerciser • Resistance band workouts • Supervised balance and mobility challenge tasks • Seated exercise groups (some run by the Parkinson's UK network)

People with Parkinson's can find more information on exercise and managing their symptoms at **parkinsons.org.uk/exercise**

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

12.2.4 Cognitive function

Tackling puzzles or logic problems exercises the brain and has been shown to beneficial for people with Parkinson's

12.2.5 Still not convinced or want to know more?

Here we get more technical and a bit less gentle! It's a section aimed at those who are unconvinced or who want to know more.

For some of us involved in the preparation of this handbook, we were told exercise is good for you, it will help your balance and mobility. However, in the early years after diagnosis, when you don't have a problem with balance or mobility, then if you don't have an exercise habit anyway, it's not a convincing argument. What we were not told, or didn't understand if we were, is that there is circumstantial evidence in people and proven evidence in mice that exercise in the early years has benefits later.

There is no technical test for a Parkinson's diagnosis. The diagnosis comes from observed symptoms. The implication of this is that the dopamine producing cells in the brain have already been affected to the extent that not only has all spare capacity been lost, but there's insufficient for base case needs, hence the appearance of Parkinsonian symptoms. Typically, for most patients, by the time they receive their diagnosis, 50% of the dopamine cells in the mid brain are lost (Dopamine). So the time to act is now. A longer explanation of the neuroprotective benefits of exercise is available from Parkinson's UK website (http://www.parkinson.org/Understanding-Parkinsons/Treatment/Exercise/Neuroprotective-Benefits-of-Exercise)

When part of the brain is damaged, other parts of the brain can be encouraged to take over the function of that area. This is known as brain plasticity. There is much scientific evidence that repetitive actions such as exercises help this process. For example, the only evidentially proven voice therapy is the LSVT course which is intensive 1:1, for one hour per day, four days per week, for four weeks (Pichler, 2005).

Studies in mice have shown long term benefits of exercise, to quote one study (Konstantinos Pothakos, 2009) :

> *This study indicates that in spite of the drastic loss of dopaminergic neurons and depletion of dopamine in the severe chronic MPD, endurance exercise training effectively reverses the Parkinson's like behavioural deficits related to regular movement, balance and gait performance.*

So you have a choice, you can continue to doubt and do nothing, and wonder later whether had you done more exercise you would have less severe symptoms now, or you can follow the recommendations for exercise and later know that you did everything you could.

In this short piece, we cannot quote you all of the research evidence, but hopefully have given you enough pointers to probe further with your consultant or Parkinson's nurse and / or do your own information gathering on the internet. There are several references at the end of this section for further reading.

Use it or Lose it

12.3 Adapting your lifestyle

Inevitably Parkinson’s is going to affect your life, but by adapting your lifestyle those impacts can be reduced.

12.3.1 Timing

There’s no mathematics behind Parkinson’s medication, it varies from person to person and is tuned to the individual by your consultant or Parkinson’s nurse.

Taking your medication regularly and at routine times is very important. You will know how long it takes for the medication to become effective, so plan your appointments and activities for the times when your medication is most effective and avoid the times just either side of your medication.

There are times when this won’t work. Suggesting your daughter re-schedules her wedding to fit in with your medication is not going to be met with any enthusiasm! More seriously, if you are going to exercise classes or similar you need to be sure that your medication is if full effectiveness for the duration of the class rather than taking meds in the middle of it. On these occasions, you need to move your medication schedule to match your commitments, ideally by advancing or retarding your daily schedule, so this might mean changing meal times etc.

For critical events, discuss taking a booster dose with your Parkinson’s nurse or specialist in the clinic. Please given them plenty of notice for this advice – it’s no use calling the morning before you fly!

If you are taking both controlled release and normal tablets you can advance the normal tablet by half an hour or so to provide additional protection at critical periods.

12.3.2 Prompts and Lists

You may find it helpful to use written prompts and lists to compensate for problems with memory, shopping, to –do, etc.

12.3.3 Equipment and aids to daily living

You can get advice about equipment from one of the many aid and equipment shops in the area. The staff are able to give information about a variety of gadgets and gizmos which make life easier. However for more pricey equipment such as bathing aids, bathroom adaptations or even stair lifts - you might be better to seek advice from the Occupational Therapists (OT) in Hampshire County Council – OT Direct who accept referrals direct from the public on 03005551378.

In addition, the Hampshire County Council ‘ Connect to Support’ Hampshire website contains:

- information and advice about independent living, care and support
- a directory of local support organisations, local activities, national charities and helplines
- a directory of care homes
- a directory of home care agencies

If you have a lot of problems with mobility and falling, you should be referred to the integrated community team for your area - but you can refer yourself ;

- 01425 627802 For Lymington and New Milton
- 02380 428488 (for Hythe, Totton and Lyndhurst).

Finally, beware of kitchen and bathroom companies who advertise in the national press that they can sort out a disability friendly bathroom - they may be adequate bathroom fitters but if you have specialist disability needs, you need advice from an OT not a salesman or even a plumber!

12.3.4 Radar Key / National Key Scheme

The Radar key has nothing to do with Radar or any other high tech devices. It's a standard key that enables people with health conditions and disabilities to access thousands of locked public toilets around the country.

Keys are available to purchase from a variety of places at various costs. However, the original supplier claims theirs are made to higher specification than others and are guaranteed to work all locks. Their price is £3. Order on line at www.radarkey.org or by phone 01395 265543

12.3.5 Travel

12.3.5.1 Driving

There are many people who continue to drive after they are diagnosed with Parkinson's. However, you must tell the DVLA and your insurance company. The DVLA will contact your GP and / or Parkinson's specialist and you will be asked to complete a PK1 form, "Medical Fitness to Drive".

In order to compete this, the doctor you have requested to do so will need to ask specific questions of you and others. It is important to be completely honest in answering these questions as it is an offence not to disclose something which may make you unfit to drive.

Sometimes the PD specialist or doctor may suggest you have a formal driving assessment in order to inform the decision about fitness to drive. This advice is usually given when it is likely that otherwise the doctor would advise that you can't drive so it is in your interest if you want to continue to drive, to make arrangements to have the assessment. The usual advice would be to contact Wessex Driveability (023 8055 4100) or https://www.wessexdriveability.org.uk to arrange an assessment.

On rare occasions the doctor may say that a patient should not drive even before reporting your condition to the DVLA - in this case, you should stop driving immediately and cannot even drive home from the hospital/surgery. If you continue to drive in this case you will be uninsured and criminal charges could result if you have an accident.

Every case is different and both your Parkinson's symptoms and your medication affect any decision. Some of the drugs used in the treatment of Parkinson's have legal restrictions on taking them and driving.

The DVLA will make one of the following decisions :

- You can keep your licence without restrictions
- You can have a short licence, valid for one, two or three years before further review
- Your licence would be restricted to vehicles with adaptations
- You must stop driving and give up your licence

If you do not heed the medical advice to inform the DVLA about your condition then it is now expected that the doctor will inform the DVLA . The rules of confidentiality do not apply in this case.

For more information, read the Parkinson's^{UK} leaflet "Driving and Parkinson's" or call their helpline at 0808 800 0303. The DVLA can be contacted at 0300 790 6806

Wessex Drivability

12.3.5.2 What if I can't drive as a result of my Parkinson's

Giving up your car doesn't mean you can't travel. 2018 research by Kwik-Fit showed the average cost of running a car in the UK was £162 per month for running costs and £226 per month for finance, which is nearly £10 per day to redeploy into other means of transport such as taxi's. In addition to public bus services, there are Cango and Community First bookable services in the New Forest. The Connect to Hampshire website https://www.connecttosupporthampshire.org.uk and it’s corresponding book, “A Guide to Better Care and Support” available from Hampshire CC Adult Services contain much more information about transport options. Also don’t forget that your attendance allowance can be used to pay for transport.

12.4 Nutrition

Eating a healthy diet In Parkinson’s disease (PD) is no different to everyday life.

However there are a number of important points to note;

- Constipation is a significant risk in Parkinson’s and therefore fruit and vegetable intake is important(at least 5 portions daily)
- Fluid intake (2 litres, 3.5 pints daily) is important to maintain good bladder function and good blood pressure and helps with constipation
- Low blood pressure can be a problem in PD- good fluid intake and a plentiful salt intake is therefore important - your PD specialist will advise if this applies to you
- Weight loss for no apparent reason is common in PD – even with a good appetite. This is why you are weighed regularly in the specialist clinic. If it applies to you , you should ensure you increase your calorie intake accordingly - halting weight loss is the most important goal in PD and trumps any concerns about cholesterol, carb or fat intake. Weight loss in PD usually involves losing lean muscle mass which contributes to falls and poor mobility.
- You may hear stories about protein in food interfering in medication absorption. Whilst there is a theoretical possibility that the effect of medication will be reduced if taken just before a high protein meal- this must not be taken to mean that protein intake should be reduced. On the contrary, people with PD are always at greater risk of malnutrition due to low protein intake than loss of medication absorption.
- People with Parkinson’s have a greater than normal risk of osteoporosis - this means high calcium and vitamin D are important. Milk intake is therefore good. Your bone health should be assessed regularly in the PD clinic – ask if you want to know more.

12.5 Living Alone

Those alone can be divided into two categories. There are those who have made the choice to live alone and there are those alone due to circumstances, usually the result of the death of a partner.

Being alone with a health problem such as Parkinson’s means deciding on a DO’s and DON’T’s list. Risk taking has to be carefully considered, which means spontaneity regarding activities should be curbed. Taking the spice out of life can be remedied by finding alternatives, for example – exercise is beneficial to PWP so if circuit training in the gym has to be stopped, join a dance class or an exercise class that is specifically for PWP.

Arrangements should be in place for any emergency, especially a detailed list of contacts. The wishes of the person alone regarding end of life care should be clearly stated and legally binding.

Think positive and have fun.

“Life is for living” means participating.

12.6 References

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13 Planning for the future and unexpected

13.1 Contingency Planning

Contingency planning is something we should all do irrespective of whether we are living with Parkinson's or not. If we're unfortunate enough to be involved in an accident and wake up unable to write our name, it's good if you've already created plans that will help you. When living with Parkinson's, it's important to put those plans in place sooner rather than later.

Item	**Yes or No**	**Date**
Princess Trust Care Plan set up		
Lions Message in a Bottle		
Emergency contact alarm (Careline)		
Lasting Power of Attorney - Health and Welfare - Signed - Registered - Activated	-	-
Lasting Power of Attorney – Property and Finance - Signed - Registered - Activated with each institution		
I have made a will		
I have documented my wishes for advanced stages of the condition (see Section 12)		

13.2 Advanced Care Planning

13.2.1 What is Advanced Care Planning?

Advanced Care Planning (ACP) is a process through which we document via discussions with our family and health practitioners our desires for how we would be treated if and when we are no longer able to express those preferences for ourselves.

13.2.2 Who does it apply to?

Everyone, healthy or otherwise.

13.2.3 Why do we need it?

Advanced Care Planning (ACP) is a difficult topic for all of us to consider at any age and whatever our health. We all would like to live to a ripe old age and then pass on with the minimum of fuss. For some of us, that will be the case, but for others, illness or accident will intervene. Unfortunately, we have no way of knowing into which of those two groups we fall, and therefore we should all consider how we would wish to be treated when we can no longer express our wishes for ourselves. It's not sufficient just to think about it, but we need to communicate it to our families and those who will be looking after us, doctors, paramedics, hospitals etc. Thankfully, the NHS has a system that allows us to do this once and for our wishes to be available for all emergency and long term care staff.

13.2.4 Why do it now?

None of us know what the future holds, we could step off a pavement tomorrow and be hit by the proverbial bus and left a shadow of our former selves. Without ACP, everyone caring for us will have to use their best judgement as to what we would have wished. With a documented ACP, they will know what we want whether or not we can express it ourselves.

13.2.5 What does an ACP contain?

An ACP begins with an expression of what's important to you and what your wishes are and then progresses through increasingly formal documents to the stage where you appoint someone to make decisions on your behalf.

13.2.5.1 Advance statement of wishes and preferences

Copied from https://www.nhs.uk/conditions/end-of-life-care/advance-statement/

An advance statement is a written statement that sets down your preferences, wishes, beliefs and values regarding your future care.

The aim is to provide a guide to anyone who might have to make decisions in your best interest if you have lost the capacity to make decisions or to communicate them.

13.2.5.2 What does an advance statement cover?

An advance statement can cover any aspect of your future health or social care. This could include:

- how you want any religious or spiritual beliefs to be reflected in your care
- where you would like to be cared for – for example, at home or in a hospital, a nursing home, or a hospice
- how you like to do things – for example, if you prefer a shower instead of a bath, or like to sleep with the light on
- concerns about practical issues – for example, who will look after your dog if you become ill

You can make sure people know about your wishes by talking about them. By writing your advance statement down, you can help to make things clear to your family, carers and anybody involved in your care.

13.2.5.3 Is an advance statement the same as an advance decision?

No. An advance decision (also known as a living will, or advance decision to refuse treatment) is a decision you can make now to refuse specific treatments in the future.

An advance decision is legally binding, as long as it meets the necessary criteria for it to be considered valid and applicable.

13.2.5.4 Who makes an advance statement?

You write an advance statement yourself, as long as you have the mental capacity to make these statements. You can write it with support from relatives, carers, or health and social care professionals.

Mental capacity is the ability to make decisions. Sometimes, people do not have mental capacity. This can be for a number of reasons, including illness.

13.2.5.5 Is an advance statement legally binding?

No, an advance statement is not legally binding, but anyone who is making decisions about your care must take it into account.

13.2.5.6 How does an advance statement help?

An advance statement lets everyone involved in your care know about your wishes, feelings and preferences if you are not able to tell them.

13.2.5.7 Does it need to be signed and witnessed?

You don't have to sign an advance statement, but your signature makes it clear that it is your wishes that have been written down.

13.2.5.8 Who should see it?

You have the final say in who sees it. Keep it somewhere safe, and tell people where it is, in case they need to find it in the future. You can keep a copy in your medical notes.

13.2.5.9 Thinking about your wishes

If you're thinking about preferences and wishes for your future care, you may find this leaflet useful: Planning for your future care (http://www.ncpc.org.uk/publication/planning-your-future-care) .

The charity Dying Matters (https://www.dyingmatters.org/overview/need-support) has information on talking about dying, and ideas and inspiration to help start the conversation, things to think about and letting people know your wishes.

13.2.6 Advance decision to refuse treatment (sometimes called a living will)

Copied from https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/

An advance decision to refuse treatment lets your healthcare team know your wishes if you aren't able to communicate them.

13.2.6.1 What is an advance decision?

An advance decision (sometimes known as an advance decision to refuse treatment, an ADRT, or a living will) is a decision you can make now to refuse a specific type of treatment at some time in the future.

It lets your family, carers and health professionals know your wishes about refusing treatment if you're unable to make or communicate those decisions yourself.

The treatments you're deciding to refuse must all be named in the advance decision.

You may want to refuse a treatment in some situations, but not others. If this is the case, you need to be clear about all the circumstances in which you want to refuse this treatment.

An advance decision isn't the same as an advance statement.

Deciding to refuse a treatment isn't the same as asking someone to end your life or help you end your life. Euthanasia and assisted suicide (https://www.nhs.uk/conditions/euthanasia-and-assisted-suicide/) are illegal in England.

13.2.6.2 Life-sustaining treatment

You can refuse a treatment that could potentially keep you alive, known as life-sustaining treatment.

This is treatment that replaces or supports ailing bodily functions, such as:

- ventilation – this may be used if you can't breathe by yourself
- cardiopulmonary resuscitation (CPR) (https://www.nhs.uk/conditions/first-aid/cpr/) – this may be used if your heart stops
- antibiotics – this can help your body fight infection

You may want to discuss this with a doctor or nurse who knows about your medical history before you make up your mind.

13.2.6.3 Who makes an advance decision?

You make the advance decision, as long as you have the mental capacity to make such decisions.

You may want to make an advance decision with the support of a clinician.

If you decide to refuse life-sustaining treatment in the future, your advance decision needs to be:

- written down
- signed by you
- signed by a witness

If you wish to refuse life-sustaining treatments in circumstances where you might die as a result, you need to state this clearly in your advance decision. Life-sustaining treatment is sometimes called life-saving treatment.

You may find it helpful to talk to a doctor or nurse about the kinds of treatments you might be offered in the future, and what it might mean if you choose not to have them.

The charity Compassion in Dying (https://compassionindying.org.uk/choose-a-way-to-make-an-advance-decision-living-will/) has an advance decision form you can fill in online or by hand, with suggestions for things to think about.

You need to register (for free) on the website before you can see the form.

13.2.6.4 Is an advance decision legally binding?

An advance decision is legally binding as long as it:

- complies with the Mental Capacity Act (https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/)
- is valid
- applies to the situation

If your advance decision is binding, it takes precedence over decisions made in your best interest by other people.

An advance decision may only be considered valid if:

- you're aged 18 or over and had the capacity to make, understand and communicate your decision when you made it
- you specify clearly which treatments you wish to refuse
- you explain the circumstances in which you wish to refuse them
- it's signed by you (and by a witness if you want to refuse life-sustaining treatment)
- you have made the advance decision of your own accord, without any harassment by anyone else
- you haven't said or done anything that would contradict the advance decision since you made it (for example, saying that you've changed your mind)

13.2.6.5 How does an advance decision help?

As long as it's valid and applies to your situation, an advance decision gives your health and social care team clinical and legal instructions about your treatment choices.

An advance decision will only be used if, at some time in the future, you're not able to make your own decisions about your treatment.

13.2.6.6 Does an advance decision need to be signed and witnessed?

Yes, if you're choosing to refuse life-sustaining treatment.

In this case, the advance decision must be written down, and both you and a witness must sign it.

You must also include a statement that the advance decision applies even if your life is at risk.

13.2.6.7 Who should see it?

You have the final say on who sees it, but you should make sure that your family, carers or health and social care professionals know about it, and know where to find it.

Your family or carers may have to find it quickly if you require emergency treatment and they need to tell the healthcare professionals your wishes.

You can keep a copy in your medical records.

13.2.6.8 CPR and a 'do not attempt CPR' decision

Cardiopulmonary resuscitation (CPR) is a treatment that attempts to start breathing and blood flow in people who have stopped breathing (respiratory arrest) or whose heart has stopped beating (cardiac arrest).

CPR can involve:

- chest compressions (pressing down hard on the chest repeatedly)
- electrical shocks to stimulate the heart (sometimes more than once)
- injections of medicine
- artificial ventilation of the lungs

In hospital, around 2 out of 10 people survive and leave hospital after having CPR. Survival rates are usually lower in other settings.

The chances of CPR working for you can be higher or lower than this. For some people, there will be no chance of benefit from CPR.

It depends on why your heart and breathing has stopped, any illness or medical problems you have, and your overall health.

Your healthcare team can discuss with you the likely chance of CPR working for you.

Even when CPR is successful, a person can develop serious complications, such as:

- fractured ribs
- damage to the liver and spleen -brain damage, leading to disability

People who survive after having CPR may need high-intensity medical support afterwards, and a small number need prolonged treatment in an intensive care unit (ICU).

13.2.6.9 Refusing CPR in advance

Everyone has the right to refuse CPR if they wish. You can make it clear to your medical team that you don't want to have CPR if you stop breathing or your heart stops beating.

This is known as a do not attempt cardiopulmonary resuscitation (DNACPR) decision, or DNACPR order.

Once a DNACPR decision is made, it's put in your medical records, usually on a special form that health professionals will recognise.

It's also helpful to let your family or other carers know about your DNACPR decision so it doesn't come as a surprise to them if the situation arises.

If you have a serious illness or are undergoing surgery that could cause respiratory or cardiac arrest, a member of your medical team should ask you about your wishes regarding CPR if you haven't previously made your wishes known.

If you don't have the capacity to decide about CPR when a decision needs to be made and you haven't made an advance decision to refuse treatment, the healthcare team may consult with your next of kin about what they know of your wishes to make a decision in your best interests.

A DNACPR order isn't permanent, and you can change your mind and your DNACPR status at any time.

You can find out more in the Resuscitation Council's leaflet about CPR (https://resus.org.uk/_resources/assets/attachment/full/0/21777.pdf).

13.2.6.10 More information

- Age UK: advance statements and living wills http://www.ageuk.org.uk/money-matters/legal-issues/living-wills/about/)(
- Alzheimer's Society: making an advance decision https://www.alzheimers.org.uk/info/20032/legal_and_financial/131/advance_decision_living_wills/8
- Compassion in Dying: making decisions and planning your care https://compassionindying.org.uk/making-decisions-and-planning-your-care/
- Dying Matters: legal and ethical issues around advance care planning, including advance decisions (http://dyingmatters.org/page/legal-and-ethical-issues)
- Dying Matters: planning ahead for your future care (PDF, 393kb) http://www.dyingmatters.org/sites/default/files/user/Planning_for_your_future_care_FINAL_010212.pdf
- Healthtalk.org: videos and written interviews of people talking about making an advance decision http://www.healthtalk.org/peoples-experiences/dying-bereavement/living-dying/advance-decision-refuse-treatment
- Macmillan: information on making an advance decision http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Advancedcancer/AdvanceDecision.aspx

13.2.6.11 Lasting power of attorney

Copied fromhttps://www.nhs.uk/conditions/end-of-life-care/lasting-power-of-attorney/

If you become unable to make decisions for yourself in the future, someone will need to make decisions for you. Who does this will depend on the situation.

Generally, professionals will make decisions about your health and social care, and your family or carers will decide on day-to-day matters.

If you wish, you can officially appoint someone you trust to make decisions for you. This is called making a lasting power of attorney (LPA), and enables you to give another person the right to make decisions about your care and welfare.

You can also appoint an attorney to decide on financial and property matters.

There are special rules about appointing an LPA. To find out more, read GOV.UK's advice on making a lasting power of attorney (https://www.gov.uk/power-of-attorney).

You can call the Office of the Public Guardian on 0300 456 0300 for forms and guidance. The Office of the Public Guardian can also provide more information on making an LPA to cover decisions on property and legal matters.

13.2.6.12 How do I get started

Think about what is important to you, what you would like or would not like to happen in the event you are not able to tell people at the time

Discuss with others so they know your wishes; family, friends, GP / nurse / consultant. Your health care professionals can guide you through the process

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14 Glossary

The descriptions of terms given here are to aid understanding rather than the scientific or specialist definitions

Term	**Description**
ADL	Activities of daily living – washing, dressing, cooking etc
ACP	Advanced Care Plan – a document describing what you want and do not want in terms of future care
ADRT	Advanced Decision to Refuse Treatment – a document which defines which treatments you do not wish to undergo
Anxiety	An unpleasant feeling of uneasiness, fear, apprehension or concern
APO	Apomorphine
Apomorphine	A strong type of dopamine agonist. Despite its name, Apomorphine does not contain morphine.
Cango	A local bust that can deviate from its set route
carb	Carbohydrate foods – potatoes, bread, pasta etc
Cardiopulmonary	Relating to the heart and the lungs
Co-beneldopa	Generic name for Madopar, a drug used for treating Parkinson’s
Co-careldopa	Generic name for Sinemet, a drug used for treating Parkinson’s
Co-dydramol	Pain killer containing paracetamol and codeine
Cognitive	Relating to the mental process involved in knowing, learning, and understanding things
CPR	Cardiopulmonary Resuscitation – an emergency procedure applied in the event of heart attack
DBS	Deep brain stimulation – a type of surgery used to control Parkinson’s
Delirium	A state of mental confusion that can happen if you become medically unwell.
Delusion	A fixed false belief, misinterpreting something that is real
Depression	A common mental health problem that causes people to experience low mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
Dopamine	In the brain, dopamine functions as a neurotransmitter—a chemical released by nerve cells to send signals to other nerve cells.
Dopaminergic	Related to dopamine
Dopamine agonist	Drugs which act like dopamine to stimulate nerve cells
Drug	A chemical which is given to people in order to treat or prevent an illness or disease

Term	**Description**
DVLA	Driver and Vehicle Licensing Agency
Dystonia	uncontrolled and sometimes painful muscle movements
Dyskinesia	Abnormal, uncontrolled, involuntary movement
Entacapone	A drug which blocks a certain natural substance that breaks down the levodopa in the body
Euthanasia	The practice of intentionally ending a life to relieve pain and suffering
Fall	A movement in which you end up in a position you didn’t intend
Hallucination	See or hear or feel things that aren’t really there
HCC	Hampshire County Council
Incontinence	The inability to control accidental or involuntary leaking of urine or stool
Libido	the human sexual urge, desire or drive
LPA	Lasting Power of Attorney
LSVT	Lee Silverman Voice Treatment – an exercise therapy for the voice
MPD	Mouse model of Parkinson’s Disease
Neurodegeneration	The progressive loss of structure or function of neurons, including death of neurons
Neurological	The science of the nerves and the nervous system
Neurons	a specialized cell transmitting nerve impulses
Neuroprotective	Protecting nerve cells against damage
Neurorehabilitation	A complex medical process which aims to aid recovery from a nervous system injury, and to minimize and/or compensate for any functional alterations resulting from it
NFDC	New Forest District Council
NHS	National Health Service
NICE	National Institute for Clinical Excellence
Osteoporosis	A condition that weakens bones, making them fragile
OT	Occupational Therapist / Therapy
Plasticity	The brain's ability to change and adapt as a result of experience or damage
PwP	Person with Parkinson’s
Prostate	A walnut-sized gland located between the bladder and the penis
RADAR	A system of traditional locks and keys used for public conveniences for the disabled
Stalevo	A combination drug used in the treatment of Parkinson’s
Suprapubic	Above the pubic bone
Tai Chi	An exercise which combines deep breathing and relaxation with flowing movements

15 Handbook Maintenance

15.1 Periodic Updates

Periodic updates will be made available through via your clinic or local Parkinson's UK branch

15.2 Additional Pages

Additional record form pages can be obtained from the DVD included with this handbook or from the Parkinson's Service secretary at Lymington New Forest Hospital.

15.3 Replacement pages

If you need replacement pages as a result of damage, they can be obtained from the pdf version of this handbook included on the DVD handbook or from the Parkinson's Service secretary at Lymington New Forest Hospital.

15.4 Corrections / queries / requests for additional content

If you spot any errors please advise handbook@parkinsonsnewforst.org

If you have suggestions for additional content please tell your Consultant or Parkinson's Nurse, or any member of the Parkinson's UK New Forest Branch Committee

16 Parkinson’ UK Order Form

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17 DVD

- Non Motor Symptoms video on DVD
https://www.youtube.com/watch?v=Zg1VaSxdbp0&t=7s

- PDF Version of this manual, with clickable links
- Blank forms in pdf format to print

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18 Spare Forms

Apomorphine pump	
My pump is administered by	
Telephone Number	
Flow Rate	
Start Time	
Stop Time	

DBS	
I have a DBS Unit. The serial number is:	
My DBS Nurse is	
Telephone	
My DBS Specialist is	
Telephone	

APO-go Pen and APO-go syringe	
I use a Pen / Syringe	Delete as appropriate
I use the following type of needle	
I use the following type of syringe	

Current Medication Plan

Name :…………..

Date : __/__/__

Medication Name								
Time / Dose								

Notes :

Name :…………..   Date : __/__/__

Medication Name								
Time / Dose								

Notes:

Medication History PD specific – variable dose – Co-careldopa, co-beneldopa, stalevo

Name :		Drug :	
Date Started :		Date Finished :	
Reason for start :		Reason for finish	

Name :		Drug :	
Date Started :		Date Finished :	
Reason for start :		Reason for finish	

Medication History - All previous and current

Medication	Dose	Date Started	Date Stopped/ changed	Reasons

Medication	Dose	Date Started	Date Stopped/ changed	Reasons

19 Pilot feedback

Please record on this page any thoughts you have about the handbook over the time that you use it.

We are keen that any record you make on this page is dated in order to see if things change over time.

We are interested to know if you have found anything helpful or unhelpful, what items were useful and when and whether you were tempted to search out any of the resources (leaflets or online info) which is mentioned in the handbook.

We would also suggest that you record if there is anything you find unhelpful or cumbersome and you are never likely to use.

Have there been any instances where the handbook has raised concerns for you or added to stress or worry – either because of anything in the content, or because you have forgotten to record something you intended to or feel you were meant to .

Have you found the handbook useful when attending clinic – or not. Has the professional you've seen in clinic been interested in your drug history for example?

Thank you for recording your thoughts in real time, when we come to evaluate the usefulness of the Handbook - we will be asking for your comments and this page will hopefully help to jog your memory.

Date	Comment
