

# Getting the most out of your Parkinson's medicines



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## INTRODUCTION

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As a person with Parkinson's you will have lots of medicines to take that are needed to maintain your ability to keep moving so you can do the things that are important to you.

Taking your medicines in the right way, at the right time, is important. However, you may have difficulties in swallowing your medicines.

Prescribing medicines for people with Parkinson's is a complex matter as your condition is ever changing.

This resource was developed to give you the power to get the best out of your medicines. It offers advice for taking your medicines from people with Parkinson's, pharmacists and speech-language therapists.

We hope you find this helpful.

## DESIGN TEAM

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## TOP 10 TIPS FOR TAKING PARKINSON'S MEDICINES SAFELY

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1	Plan for your doctor's <u>visit</u> , use the online tool <u>here</u> and use your <u>Symptom Diary</u> .
2	Consider keeping a symptom diary so you can remember how you have been feeling since your last doctor's visit. What do you think made your symptoms worse? What made you feel better?
3	It is ok to ask questions about your medicines. If you need to, get your whanau and friends to ask for you.
4	<p>Get to know what your medicines are and what they are for, how and when to take them, and their common side effects:</p> <ul style="list-style-type: none"> <li>• <u>My Medicines</u> Patient Medication Information Leaflets (English) (Search for your medicine by brand or chemical name)</li> <li>• <u>My Medicines</u> Patient Medication Information Leaflets (Te Reo) ( Search for your medicine by brand or chemical name)</li> <li>• <u>Health Navigator</u>: Parkinson's Medication (English)</li> <li>• <u>New Zealand Formulary</u>: Drugs used in parkinsonism and related disorders – Parkinson's disease</li> <li>• <u>Medsafe</u> Medicines Data Sheets and Consumer Medicine Information (Search by medicine brand name or chemical N=name)</li> </ul>
5	Know what to do if you miss a dose and make a note in your symptom diary of what happened and what you did in response.

6	<p>Be honest when asked about how you usually take your medicines, this will help you and your healthcare team to find what will work best for you. It is important that everyone knows what you are taking and how this is working for you, so you get the most benefit from your medicines and ensure you are happy with your regime.</p>
7	<p>Make sure you have an up-to-date list of all the medicines you are taking, including medicines you buy yourself and herbal remedies. Ask your pharmacist to make sure they are safe to take together. Ask your pharmacist for advice before taking anything new.</p>
8	<p>Ask your pharmacist before crushing, chewing or halving any medicines.</p>
9	<p>It is usually best to take medicines with water, but if this is difficult, talk to your pharmacist or speech and language therapist about other options.</p>
10	<p>These swallowing tips may help you:</p> <ul style="list-style-type: none"> <li>• Take your medicines one at a time with fluid. It may be easier to take them with a thicker fluid, like yoghurt. Ask your pharmacist to check if this is recommended with your medicines.</li> <li>• Some of your medicines may be available in liquid or as dissolvable tablets – check with your GP and pharmacist.</li> <li>• If you have reflux, talk to your doctor, they may be able to prescribe something to help you.</li> <li>• Take your medicines while sitting upright (if possible) and try not to tilt your head backwards.</li> <li>• Ask if you can see a speech language therapist to help you with tips to help with swallowing.</li> </ul>

## MEDICINES REMINDER APPS

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Many people find that apps and tools help support a regular medicine regime on a day-by-day basis. Dip into this if you haven't already done so and see if there is anything that may be helpful for you.



**Medisafe (free app)**



**Tab Timer (Vibrating pill timer reminder)**



**MyTherapy (free app)**

**MedMinder**

**Med minder**  
**(Automated Pill Dispenser)**



**PD Me Tools**  
**(iTunes app)**



**@Point of care**  
**(Parkinson's Manager App)**

## WHAT DO PEOPLE WITH PARKINSON'S SAY ABOUT TAKING THEIR MEDICINES?

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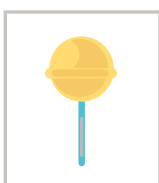
**"I manage my pills best with thicker things like jam, yoghurt, honey"**



**"Juice and milk are easier than water"**



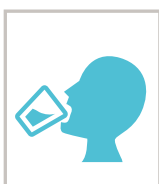
**"I lean forward before I take medication"**



**"If I'm out I always suck a lolly first to get my saliva going before swallowing my pills"**



**"Small ones together, large ones one at a time"**



**"A hard effortful swallow works"**



***"Stewed apple helps."***



**"Some of my pills I can dissolve in water"**



## TIPS FOR TAKING MEDICINES

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People with Parkinson's have used the following strategies to keep on target on time.

- **"I have a Tabtimer watch with four alarms set for tablet taking times. This works mostly."**
- *"I have set the alarm on my mobile to remind me when tablets need to be taken."*
- *"Sort the medications in the morning putting the midday and evening lots into separate vials".*
- **"I have an alarm to remind me to take medications during the day, and I usually take them with a glass of water."**
- **"I have alarms on my android phone."**
- *"I put my doses in 4 plastic boxes the night before."*
- *"I rely on memory and always carry a small container of tablets with me".*
- **"I use the iPhone app Medisafe with a notification function."**
- **"I put my meds in a 7-Day AM/PM pill organizer container a week at a time."**
- *"I use printed spreadsheet with times and medication set out."*
- *"I use a small pill holder."*

## WHAT DO SPEECH THERAPISTS SAY ABOUT TAKING PARKINSON'S MEDICINES?

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- 1** Take your medicines one at a time with fluid. It may be easier to take it with a thicker fluid, like yoghurt or stewed apple puree. Ask your pharmacist to check if this is recommended with your medicines.
- 2** Some of your medicines may be available in liquid or as dissolvable tablets – check with your GP and pharmacist.
- 3** If you have reflux, talk to your doctor, they may be able to prescribe something to help you.
- 4** Take your medicines while sitting upright (if possible) and try not to tilt your head backwards.
- 5** Ask if you can see a speech-language therapist to help you with tips to help with swallowing.

## WHAT DO COMMUNITY PHARMACISTS SAY ABOUT TAKING MEDICINES?

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### **Do ask your pharmacist\*:**

If you would like more information about any of your medication.

### **Do come and see us without an appointment:**

Or call us during business hours if you have any questions about taking your medications.

If you have a lot of questions or would like to spend some dedicated time with a pharmacist, call us in advance so we can recommend a good time to come in.

### **When you are meeting with your pharmacist\* do let them know:**

If your medication schedule does not suit your lifestyle, they might have suggestions that can help you.

If you are worried about side effects refer to your [Symptom Diary](#) (if you are using one).

If you have problems swallowing, we can help you find a way to take your medications safely. Alternatively, you can see a speech-language therapist about tips to help with swallowing.

If you have questions, it is better to ask them early on so that you can keep on top of your condition. We can work together to find solutions that work best for you.

**You may like to keep a diary** of when you do and don't take your medications, and the symptoms you have. This can help you and your healthcare team to understand what is working well for you, and how we can organize your medications to suit your lifestyle.

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**Do keep a list of your medication and times you take them:**

This is especially important if you are going into hospital or on holiday so other health professionals can see what you usually take and when.

A medication list is also called a "yellow card" in NZ and your pharmacist can provide you with this.

**Don't try to manage side effects on your own:**

Your pharmacist or doctor can help you with this.

**Don't forget to take your medication:**

If you are having trouble remembering when to take them, your pharmacist can suggest some ways to help you. See previous list of tips.

**Don't purchase any over-the-counter medication:**

Or vitamins from the supermarket or health store without talking to your pharmacist first.

\* or nurse or doctor, depending on where you live and your situation

## GETTING THE MOST OUT OF YOUR TIME WITH YOUR SPEECH THERAPIST

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### 1. Self-refer early

Don't wait until your voice, speech or swallowing is so bad you can't cope. Your speech-language therapist can provide exercises to maintain your physical function and can provide strategies to prevent choking or weight loss.



### 2. Services delivery options:

- Hospital, outpatient or home-based
- Private practice
- University-based clinics and research studies
- Talk link for specialist communication equipment provider



### 3. Be prepared

Speech-language therapists support people across the lifespan with communication and swallowing difficulties. Make sure you are ready with questions about taking your medications as well as your mealtimes and communication. Have all your medicines out and make sure you know which can be crushed / halved etc.



### 4. Written information

Make sure you write down the speech-language therapist's suggestions or ask for some written information.

## GETTING THE MOST OUT OF YOUR TIME WITH YOUR COMMUNITY PHARMACIST

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### 1. Come and see us anytime



Most community pharmacies are open every day, and there is always a pharmacist there who can help you with your medications. It's ok to ask, especially if there is anything that is worrying you about your medicines. They can find the information for you or direct you to someone who can help.

### 2. We have private consultation rooms



Every pharmacy in New Zealand has a private consultation room so you can discuss your medicines in a quiet place. If you have a lot of questions, your pharmacist might recommend coming to visit at a time that is not too busy so you can discuss your medicines in more detail without being disturbed.

### 3. We need to know what you are taking



To help you to get the best from your medications, we need to work together. We need to know if you are taking or thinking about taking any other medicines that you buy yourself such as vitamins, supplements and over the counter medications. This will help us to give you the best advice and check your medicines and vitamins are safe to take together.

It is also essential for you to tell us exactly how you are taking your medications and if you have trouble remembering to take them, or difficulty swallowing them. We may be able to help you with these things.

You may be able to register with the *Long Term Conditions Service* at your pharmacy to receive extra support from them.



#### 4. Let us know if you are worried about side effects

We can help you to understand the side effects that can happen and what to do if you experience them. It's important you know what to expect and what to do if side effects occur.

#### 5. Ask for written information



Your pharmacy can provide you with written information about your medicines or may recommend a website to go to for more details.

They can also give you a printed list of your medicines or fill in a yellow card for you, so you have an up-to-date list of what you are taking, and when it is best to take them.

Although they are the professionals when it comes to medications, you are the expert when it comes to you and things affecting your life.

#### 6. Places to go for more information



If you would like to find more information about your medications, there is a list of resources that might be helpful here:

- [My Medicines](#) Patient Medication Information Leaflets (English and Te Reo ) - Search for your medication by brand or chemical name
- [Health Navigator](#): Parkinson's Medication
- [New Zealand Formulary](#): Drugs used in parkinsonism and related disorders -Parkinson's disease
- [Medsafe](#) Medications Data Sheets and Consumer Medication Information (Search by brand or chemical name)

## GETTING THE MOST OUT OF YOUR TIME WITH YOUR NEUROLOGIST OR DOCTOR

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1. Make it your standard practice **NOT** to attend meetings with neurologists or other doctors on your own. **Bring your whanau member – spouse, partner or close friend** with you to your appointment. They offer another perspective on issues, and they can help you record/remember things that were discussed.



2. Before the meeting – **PREPARE**. It is not in your interest to just turn up and leave it all the doctor.



3. Go to your appointment with a **written list of questions** you would like answered. These will come from your work done to assess your symptoms completed earlier, your identification of your own priorities and issues and the ideas you have for changes that would be beneficial to you.



4. You should assume that **the doctor will be interested in your perspective**. After all you are the subject of this relationship. So, take the initiative and put your questions and ideas on the table. They will become the agenda for the meeting; you are the chairperson!



5. **Ask for options and consider other treatments**. If you are experiencing problems with a treatment, let your doctor know or discuss it with a pharmacist.





6. **Report all your symptoms**, responses to medications and changes, no matter how unimportant you think they are. Record when the change or symptom began; when it occurs; how long it lasts; if it is constant or intermittent. Tell your story with confidence. You are the expert on you!



7. Appointments with specialists can take months to organize. If you are experiencing problems between appointments, **be proactive** and bring them to the attention of the nurse specialist or your family physician (GP). The nurse specialist may be able to help you directly and they may be able to communicate quickly with the neurologist and suggest options for you to consider.



8. Make sure that your neurologist, nurse specialists and GPs are aware of any **supplements** you are taking or **complementary therapies** you may be using. These need to be considered in the context of your overall care plan.



9. **Understand any plans made, before you leave the doctor's office.** Take notes yourself or have your support person do that for you.



10. **Be sure to ask for clarification** of anything needing further explanation before you leave the meeting.

## P.L.A.N

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**Let's PLAN for better care** is a health literacy initiative to help people prepare well for their visit to the GP or other primary care health professional.

**P.L.A.N** stands for:



### Prepare for your visit

- Write down your main concerns or questions
- Make a list of your medications and supplements
- Did you know you can take a support person with you and ask for a translator?



### Listen and share

- Say if you don't understand and if a drawing could help
- Say if you're having problems with your medicines or treatment, or can't afford them
- Is there anything else you can tell your doctor or nurse about your health?



### Ask questions

- What is my health problem?
- What happens next?
- Why is that important?
- Are there any other options?
- What can I do to help with my health?



**Note** down what you need to do next

## RESOURCES

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### **New Zealand Health Quality & Safety Commission Links**

- [Information about medications](#)
- [Let's PLAN for better care](#)

### **New Zealand Health and Quality Safety Commission – My Medicines**

[My Medicines](#) provides information for patients about medicines used in New Zealand. Search for your medicines by brand or chemical name. Information available in [English](#) and [Te Reo Māori](#).

### **Medsafe**

[Medications Data Sheets](#) and Consumer Medication Information (search by medication brand name or chemical name)

### **Health Navigator Links**

[Parkinson's overview](#)

[Parkinson's medicines](#)

[Questions to ask about your medicines](#)

[Symptom Diary](#)

[Symptom checkers](#)

### **Parkinson's New Zealand**

[Medications booklet](#)

[The Unified Parkinson's Disease Rating Scale \(UPDRS\)](#)

## RESOURCES

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### **Parkinson's UK**

[Parkinson's drugs explained – YouTube video](#)  
[Monitoring your Parkinson's](#)

### **New Zealand Formulary**

[Drugs used in parkinsonism and related disorders](#)

### **Pamphlet – Does taking your medicines ever get complicated?**

<https://tas.health.nz/assets/Publications/Pharmacy-Documents/Long-Term-Conditions/CPS026LTCPatientLeaflet080615.pdf>

### **References for Health Professionals**

[Crushing Guide resources](#)