Taking medicines the right way: what do people with Parkinson’s do?

Many people with Parkinson’s have problems swallowing, but they need to take many medicines to lead an independent life. It is more important for people with Parkinson’s to take their medicines on time compared with other patient groups. If they take their medicines late, or miss doses, their symptoms will not be well controlled and this will reduce their quality of life. Most health professionals are unaware of the daily challenges that people with Parkinson’s and their carers face.

The aim of this study was to find out how people with Parkinson’s in New Zealand take their medicines; the challenges they face, and what support they receive. An online survey was developed by people with Parkinson’s, speech-language therapists and pharmacists. The survey asked about people’s swallowing difficulties, the medicines they take and the coping strategies you use.

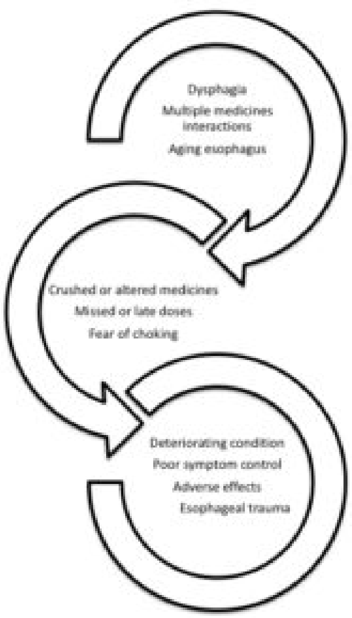

Fig. 1.

Seventy-one people with Parkinson's responded to the survey (approximately 70% male, average age 72 years, and with an average of 9 years with Parkinson's). We found that patients took a wide range and number of pills. They took an average 11 pills per day, with some taking up to 25. Some of these medicines were to help with Parkinson’s, some were to help with other issues related to

Parkinson’s such as having trouble sleeping, or with anxiety. Other medicines are needed to help manage side effects from all of their medicines. Many people with Parkinson’s also had other conditions they are managing such as asthma and diabetes, increasing the number of pills they need to take each day.

Almost 60% of people had problems with their pills, and many missed taking their medicines and needed reminders. Some people crushed tablets, used yoghurt or fruit juice, and tried other things to help with their swallowing (such as tilting their head, putting their chin down and changing where they put pills in their mouth). We found it is difficult to predict who would have problems swallowing, and who would have more medicines they needed to take from their age or number of years they had had Parkinson’s. Most people had not received any education or support with how to take their medicines.

Although we know that some support is provided by health professionals, this is not always easy for patients to understand and they don’t always remember the information given. Patients were looking for information from a variety of sources, which may not be reliable. It is important that patients are comfortable about sharing their experience with health professionals and asking questions about their care. Equally health professionals need to make sure their patients have a good understanding of how to best manage their symptoms, and take the time to listen to their needs.

Ideally medicine education should be accessible and free of medical jargon and a simple written summary should be provided of all information discussed over the counter at the pharmacy or during conversations with the doctor. The development of educational packages for people with Parkinson’s, and people involved in their care is much needed. We are developing a patient-led online resource for people to access relevant easy-to-read information for people with Parkinson’s and their carers.

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