

Understanding Parkinson's for health and social care staff

The phases of Parkinson's

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Phase	Percentage of people with Parkinson's in this phase	Average length in years	Character
Diagnosis	11%	1.6	Post diagnosis before symptoms have become significant
Maintenance	40.4%	5.9	Symptoms significant but largely controlled by treatment
Complex (advanced)	33.6%	4.9	Aim is optimal symptom control
Palliative	15.1%	2.2	Dignity and alleviation of distress

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Diagnosis

This phase refers to the point when the person receives their diagnosis. We expect people to receive an appropriate diagnosis. This means that a person diagnosed with Parkinson's should be provided with all the information they need to help them to adjust to life with the condition.

Being diagnosed with Parkinson's can be an emotional experience and everyone will react to the news in their own way. Not everyone will want a lot of information or detail about Parkinson's straight away. But it is very important that they know where to access more information and support when they are ready for it.

Think about your own experiences either personal or professional. How might you feel at this point?

The appropriate process for diagnosis as discussed in [Section 1.8](#). SIGN and NICE guidelines recommend that if a GP suspects that a person has Parkinson's, they should be referred untreated to a specialist in movement disorders before any treatment is considered. This can be a neurologist or elderly care physician.

Not everyone will immediately go on to a medication regimen at the point of diagnosis. If symptoms are mild, some people, together with their specialist, may decide to postpone drug treatment until their symptoms increase.

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Maintenance

By this phase a person's symptoms will have increased significantly. Most people will be on a medication regime to control their symptoms. A person's condition and medication regime should be reviewed every six months to make sure that they have the best quality of life possible

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Complex (advanced)

This is the point when you are most likely to come into contact with a person with Parkinson's in your workplace, so this is the phase we are focusing on in this course. In the complex phase of Parkinson's, the main issue is symptom control. People's medication regimen will be altered frequently to meet the changing nature of the condition. People with Parkinson's in this stage of the condition are likely to be taking a large number of medications and experiencing significant side effects.

People will be finding activities of daily living difficult to manage at this stage. It is very likely that many will have to give up a number of hobbies or leisure activities that they have previously enjoyed.

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End of life (palliative phase of the condition)

The major challenge in this phase is to achieve the best quality of life and maintain a person's dignity. Appropriate pain control and support services should be in place.

A person in this phase of their condition may need regular reviews of their medication. Many people may need to stop taking some medications because of an increased sensitivity to side effects or because they are not working as well as they used to. Some people may also be unable to take medication orally.

A local Parkinson's nurse or the person's specialist can provide advice about how this period should be appropriately managed.

Although the condition progresses differently and at a different speed for each person, the palliative phase can potentially cover a long period of time. Some of the more advanced symptoms can lead to increased disability and poor health. This can make someone more vulnerable to infection. People with Parkinson's most often die because of an infection or another condition.

The care plan of someone with Parkinson's should include details of their wishes for end of life. This will include who they want to be with them, any spiritual or religious needs, and where they want to be when they are dying. This may or may not be where they currently live.

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