



American Parkinson Disease Association

介紹帕金森氏病



約瑟·弗曼醫生 撰 (By Joseph H. Friedman, MD)
美國帕金森氏病協會資訊與轉介中心主任



AN INTRODUCTION TO PARKINSON'S DISEASE

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美國帕金森氏病協會(APDA)歡迎您

本會是一所非牟利團體，於四十四年前在紐約洲成立，立會宗旨是爲了「紓解煩惱，尋找治療」。現時本會設有六十個支部，六十二所資訊及轉介中心，每年撥款支助研究計劃超過三百五十萬美元。本會引導在各國推動成立帕金森氏病人協會，又創立世界帕金森氏協會，並爲帕金森氏病人及其家屬提供不同語言的教育資訊。

歡迎您蒞臨本會，我們會竭誠爲您提供協助。

Translation by Judith A. Whitbeck, Ph.D. and Joseph Tse-Hei Lee, Ph.D.



(A)何謂帕金森氏病？

帕金森氏病是一種阻礙患者活動能力的疾病。常見徵狀包括：震顫、動作遲緩、僵硬、平衡困難、言語障礙、身體屈曲困難、起步及停步均有困難。這病並不會縮短壽命，一般也不會影響記憶力和智力。

帕金森氏病的成因不明，醫學界仍在致力研究。我們對此病所知甚少。帕金森氏病一般與遺傳沒有直接關係，故此患者的家人和子女一般不會是此症的高危患者。帕金森氏症是一種腦部失調的疾病。由於腦部內一個負責協調動作的小區的腦細胞(稱為「神經元」)死亡，導致由這些腦細胞製造的化學物質減少，影響腦部控制活動的能力。有關的化學物質名叫「多巴胺」(Dopamine)。因此，帕金森氏症是由於腦部正常的化學物質分泌失衡所引致。

(B)誰會患上帕金森氏症？

大多數個案顯示，此病不是家族遺傳病。兄弟、姐妹、兒女、孫兒女不會比其他人更容易染上此病。老人往往更容易患上帕金森氏症。大約有一半患者平均在六十歲前最早發病，另一半則在六十歲或以後。由於帕金森氏症不會縮短壽命，不少患者仍會自然長老，有些人是因為到了年老才患上此病，但更多人是因為隨著患上此病而年老。在六十歲前就染上此病的人中，不少是在五十歲前後發病，有些則在甚至在四十歲前後，很少是在四十歲前發病。不過，確實有人早在這些年齡就患上此病，甚至曾經有十歲以下的兒童患者個案，不過這麼年輕的個案是極端例子。

(C)你如何知道自己患上帕金森氏病？

帕金森氏病並無診斷方法。所有腦部測試方法，包括腦波、電腦掃描、磁力共震、血液檢測、骨髓檢驗，都是一般診斷帕金森氏症的方法。有時醫生進行這些測試的目的，是為排除病人可能患上帕金森氏病以外的疾病，因為這些測試的其中一種都有可能驗出帕金森氏病。帕金森氏病是按照患者的病歷和神經檢測結果作出診斷的。

帕金森氏症患者的常見徵狀是震顫、動作遲緩，在發病超過六個月至兩年內身體失法活動能力，或者拖著腳行走。

震顫最常見於手指或手部，可波及下頷骨和腳部，多由一邊身慢慢擴展到同一邊身。當手腳靜止時，震顫便會出現，變換位置或運動時震顫便會停止，若保持著同一姿勢震顫又會出現。震顫的情況在日間病情反復，原因不明。在病人情緒激動或精神緊張時會加劇，當情緒放鬆時完全消失。當病人手持大而輕重量的東西時，如報紙，震顫至為明顯。因此閱報的動作最容易顯出震顫。震顫通常在沉睡時消失，因為病人正在入眠，故不會意識到。患者往往因為身體的顫動或者因震顫所發出的聲響而影響入睡。

動作遲緩普遍對病人構成最大的不便，儘管一般人不明白箇中原因。其中一件家人最先發現的是，患上帕金森氏病的人因為動作遲緩，令他們往往花長時間去做事情，如洗澡、穿衣、煮食、寫支票，這些動作變得愈來愈慢。既然患者是老人，人們就干脆怪罪於年老，說：「爺爺真慢，當然啦，他老了。」但帕金森氏病所引致的動作緩慢程度，比身體因自然衰老所導致的動作緩慢發展得更快，原因是患者失去了常人的活動能力。常人能輕易地扣上鈕釦；帕金森氏症病人卻要一步一步地引導其手指完成動作，就像操作機械人或者機器一樣。舉個例子，一位半身受到影響的患者說：「我那沒有障礙的手能運作自如；但我卻必須有意識地操作另一隻有問題的手，才能完成動作。」失去自主能力或者身體不由自主的動作，解釋了為甚麼帕金森氏症病人有運動障礙(akinetiC)，即一動不動或者姿勢不變。病人比常人少眨眼睛，因此他們看起來像盯著別人看。他們又比常人少吞嚥，因為唾液積聚而導致大量流涎。坐下時維持不變坐姿，恰似一尊人像，而常人卻會轉換坐姿，或交叉雙腿、或手抓面頰，還有其他小動作。

肌肉僵硬是帕金森氏病的另一徵狀。患者本人未必注意到，故醫生會替病人進行手臂、腳部和頸部測試。病人的面部也會僵硬，目無表情，而除非帕金森氏病引致其他異常姿勢，否則這些僵硬問題並不為人注意。帕金森氏症病患有肢體屈伸障礙，腰部前傾而肩頭更前傾，這種姿勢令患者比站立時看上去更蒼老，坐下時出現頭向前傾和上臂內收。

患者走路時兩臂擺動幅度有限，肩部內收，碎步，拖步以至於發出聲響。轉身也因僵硬而受阻，往往要分開小步才能轉身。

此外，患者有書寫困難，除了書寫緩慢和手顫之外，字體會愈寫愈小。最有效的檢測方法就是比較患者近期和數年前的支票簽名。患者又會出現說話障礙，聲線小，之後說話逐漸變得結結巴巴。大部分患者會發展成情緒抑鬱，另一些則出現記憶障礙。

(D) 帕金森氏症的病情發展速度如何？

病患者的病情進展不一樣，但它不會自行痊癒。所有患者的病情都會加深，某些患者的情況似乎穩定下來，是因為病情進展十分緩慢而已。許多患者在五年之內因為動作遲緩而生活習慣被迫改變。將來的情況難以預計，評估生活會怎樣受到影響的最有效方法，是比較六個月至一年前後的病況。同一程度的病情轉變很有可能在未來的六個月至一年內發生。帕金森氏症不會突然惡化。這病並不像中風或多重硬化結(Multiple Sclerosis)，帕金森氏症的病情進展較緩慢和穩定。

(E) 有甚麼治療方法？

現階段未有任何根治帕金森氏症的有效方法。死去的腦細胞無法取代和再生。

治療方法分為兩方面：首先，如何減慢病情；其次，有甚麼措施對付震顫、僵硬、動作遲緩、步行障礙。

未有任何藥物能幫助減慢動作遲緩、僵硬以及未經治療的輕微病徵。

所有治療帕金森氏症的藥物，都旨在局部改善因腦細胞死亡影響多巴胺分(Dopamine)泌，而造成腦部內的化學物質失衡。由於沒有藥物能幫助控制諸如震顫、僵硬、動作遲緩、活動能力降低等癥候，因此，只有清楚有關藥物的特性才去服用。要是一種治療某種病徵的藥物無效，那麼病人就要增加劑量，或者改用另一種藥。通常患者需要兩至三種，甚至更多種的藥物，這還未包括用以醫治其他病況的藥。

左旋多巴(L-DOPA)是治療帕金森氏症最重要的藥物，心寧美(Sinemet)是國際上通用的藥物名稱。左旋多巴是腦部的化學物質，作用是幫助腦細胞製造多巴胺。患者服用左旋多巴後，腦部就會產生多巴胺，局部改善這化學物質之遞減。不幸地，左旋多巴並不能使患者完全回復正常，在服藥一段時間後，不少患者都會出現副作用(下文討論)。很多醫生都避免處方心寧美給病況輕微，或者仍在發病初階段的患者，除非病況構成生活或工作障礙。不少人相信服用左旋多巴五年後就失效，這是不正確的。

普拉克索(Pramipexde)、羅匹尼羅(Ropiniroll)、羅天利特(Rotigotine)和溴隱亭(Bromocriptine)都具有多巴胺的作用，幫助改善因多巴胺不足所引致的毛病。但多巴胺本身卻不能直接通過「血腦屏障」進入腦部。

金剛胺(Amantadine)的作用和多巴胺的替代藥相似，其作用是干擾引致減少多巴胺的化學物質，是惟一最有效的藥物，用以幫助減低因長期服用左旋多巴而引起的運動困難和誘發性運動障礙。

有一種稱為「抗膽鹼能藥物」(Anticholinergics)，其作用是封鎖原本由多巴胺控制的一種化學物質。當腦部的多巴胺偏低，乙酰膽碱(Acetylcholine)就會過多，抗膽鹼能藥物(Anticholinergics)，加上安坦(artane)、苯甲托品(cogentin)、開馬君(kemadrin)、巴息多(parsidol)、安克癩(akineton)，能夠局部阻礙乙酰膽碱(Acetylcholine)。抗膽鹼能藥物最有效改善震顫和僵硬，但對動作遲緩和步行障礙則作用不大。還有另一些藥物對治療帕金森氏病皆有療效，雖然未必都能改善震顫。這些藥物都有不少副作用，以致限制了其功效。

(F)這些藥物有甚麼副作用？

跟所有藥物一樣，治療帕金森氏症的藥物都會產生副作用。左旋多巴的副作用可以出現在服用的早期或晚期，本文最後才討論。由於帕金森氏症是腦部失調的疾病，因此所有用以治療此病的藥物必須針對腦部。然而，與帕金森氏病有關的化學物質同時影響記憶力、智力、做夢、情緒，副作用也因而有時在這些方面發生。當病人停止服藥數天，所有副作用會隨之消失。

溴隱亭(Bromocriptine/Parlodel)、普拉克索(Premipexole/Mirapex)、羅匹尼羅(Ropinirole/Requip)和羅天利特(Rotigotine/Neupro)會引致噁心、嘔吐、站起來或坐下時眩暈、精神錯亂或產生幻覺。

金剛胺(Amantadine/Symmetrel)會引起腳腫、雙腿皮膚出現網狀青斑、精神錯亂或產生幻覺。

「抗胆礮能藥物」(Anticholinergics)會引致口乾、便秘、記憶力衰退、精神錯亂或產生幻覺。另因這藥會導致青光眼，故宜在眼科醫生指導下服用。

服用左旋多巴(L-DOPA)的早期會出現噁心、失眠、視幼覺、精神錯亂和性情改變，其中最特殊的副作用是夢境十分真實。服用多年後患者會產生另一種新的不自主動作，稱為「誘發性運動障礙」，患者的頭、手或腳出現一些無法自我控制的動作。這種狀況一般都不會影響患者，但有時患者卻會因為這些動作而衍生出問題。

大部分藥物都有助病人改善病情而不產生副作用。意識到副作用是重要的，但卻不應因而害怕服藥。所有藥物對某些人都會產生副作用，即使「代糖」對一些人都有副作用。

(G)你可以為自己作甚麼？

認識帕金森氏症和其治療方法，有助你和你的醫生更有效地溝通。服用抗帕金森氏病藥是為改善病人的感覺和行動。要是一種新藥無效，就應該通知醫生，看看是否需要增加劑量或者停止服用。許多病人不這麼做，只是繼續服用無效的藥。告訴醫生副作用引致不適也很重要。副作用的出現不表示有人犯錯，你應該把副作用的情況告之醫生。不少病人因為副作用而不再服藥，又不讓任何人知道。又有病人在服藥後出現新病情時，就怪罪於帕金森氏病本身或者抗帕金森氏病藥。

因此，誠實地將你的問題告訴你的醫生是很重要的。

服藥加上另一些治療，有助改善帕金森氏病患者的活動功能。運動十分重要。我們常常喜歡說這兩句話：「不動則鏽」，「不用則廢」。散步、舒展運動、健身腳踏車、游泳，以及其他運動都能令你感覺好一點。帕金森氏病會導致你容易疲倦，因此不要怕在運動後稍作休息，也要分開時間來做運動。

帕金森氏病患者為未來作的最有效投資，就是保持活躍：保持身體上、社交上和精神上的活躍。

(H)本地的帕金森氏病組織如何能協助？

美國帕金森氏病協會資訊及轉介中心十分樂意協助你。這組織不會提供直接幫助，但他們誠意協助你認識帕金森氏病、有關的治療方法、以及本地有甚麼資源供你使用。他們提供的教育和支援計畫，讓你更容易面對帕金森氏病的挑戰。



A) What is Parkinson's disease (PD) ?

Parkinson's disease is an illness that affects one's ability to move. It causes tremors, slowness, stiffness, poor balance, speech changes, stooped posture and changes in walking. It does not shorten lifespan much and usually does not affect memory or the ability to think.

We don't yet know what causes this disease, but many scientists are actively working on this problem. We do know a lot about this illness however. It does not usually run in families so the children and grandchildren of people with PD are usually not at increased risk. PD is a disorder of the brain. In a very small region that is very important in coordinating movements the brain cells, called neurons, die. As a result, the chemicals made by these cells become low causing problems with the brain's ability to control movements. The name of the most important chemical that is in short supply in PD is dopamine. Thus, in PD, there is an imbalance of the normal chemicals in the brain.

B) Who Gets PD?



In most cases PD does not run in families. Brothers, sisters, children and grandchildren are not more likely to develop PD than anyone else. PD tends to affect older people. About half the people who get PD have their first symptom before the age of 60 and the other half begin at 60 or later. Since PD does not shorten lifespan much most people who have PD tend to be old, some because it first developed when they became old but most because they grew old with their PD. Of the people who developed PD below the age of 60 most are in their fifties, some in their forties and very few younger than 40. But it does occur at these young ages. There is even a child who developed it under 10, but this early an onset is extremely rare.

C) How do you know if you have it?

There is no test to diagnose PD. All tests such as the brain wave (EEG), CAT scan, MRI, blood tests and spinal fluid tests are normal in PD. Sometimes doctors do these tests to be sure they are not dealing with a different illness than PD which might show up on one of these tests. The diagnosis of PD is made on the basis of the patient's medical history and neurological examination.

The usual history for someone with PD is of a gradually increasing tremor, increasing slowness, loss of mobility or shuffling while walking that has developed over the last six months to two years.

The tremor typically affects the fingers or the hands but may affect the jaw or feet. It may occur on one side or both and be stronger on one side than the other. The tremor occurs when the limb is resting, goes away during movement and may return when the limb is held out in a fixed position. For reasons not yet understood the tremor varies during the day. It becomes stronger when the person is nervous and may even go away completely when the person is very relaxed. It is amplified when the patient holds a large, lightweight object such as a newspaper so it is very common for the tremor to be first noticed while reading the newspaper or a magazine. Tremors always disappear during deep sleep but the patient cannot tell this because he's asleep! Tremors that may occur during night sleep and awaken the patient can interfere with falling asleep either because the movement is annoying or because of the



sound caused by the shaking.

Slowness is often the biggest problem for the Parkinsonian although it is not always clear to others. One of the first things that family members notice is that the Parkinsonian takes longer to do everything. Bathing, dressing, cooking meals, writing checks, all keep taking longer and longer. When the patient is old, everyone simply blames old age. "Of course, grandpa is slow, he's getting old." But this slowness gets worse rather quickly in many cases, quicker than simply growing old. The reason for this is that Parkinsonians lose some of the automaticity for movements that normal people have. If a normal person wants to button a shirt she simply "does it". A Parkinsonian must guide the fingers through the process, in some ways like guiding a robot or a piece of machinery, step by step. For example, a patient who was affected by PD on only one side of his body said, "When I use my good hand it does everything by itself. When I use my other hand I have to consciously control it and tell it what to do." This loss of automatic, or unconscious control of movements explains why Parkinsonians are "akinetik," that is, lacking in movements or "statue-like". Parkinsonians blink less than other people so they seem to be staring. They swallow less than others so they may drool due to the accumulation of saliva in the mouth. When seated they stay in one position, like a statue, whereas other people tend to shift position, cross their legs, scratch their face and perform other little movements.

Stiffness is another feature of PD. The Parkinsonian may or may not feel this but the doctor will test the arms, legs and neck for this in the office. The face also becomes stiff and looks somewhat frozen. It isn't known if the stiffness of PD causes the abnormal posture of the Parkinsonian. PD patients tend to be stooped. They tend to bend forwards a little bit at the hip and a bit more at the shoulders. This makes them look older than they really are when they stand up. While seated there is also a tendency to have the head bent and the shoulders rounded.

The walk of a Parkinsonian looks like that of an elderly person. The shoulders are stooped, the arms are held at the side or swing only to a small degree and the heels often scuff the floor causing a shuffling walk. Turning is altered as well. Parkinsonians generally turn in a series of steps rather than by pivoting. In addition to the above features other changes occur as well. Handwriting suffers. Not only is there a problem due to slowness and tremor, but the writing becomes small as well. The best way to see this is to compare signatures on recent checks with those from a few years ago. Speech often changes. The voice becomes soft and sometimes a stutter develops. Depression occurs in a large percentage of Parkinsonians and some also develop memory problems.

D) How Quickly Does PD Progress?

PD is a very variable illness, but it never goes away or gets better by itself. In all cases the illness progresses but in some people it appears to be stable because the progression is so slow. In most cases the slowness caused by the disease forces changes in lifestyle within 5 years. It is impossible to predict the future. The best guide for gauging what life will be like in the future is to look back six months or a year to see what changes have occurred during that time. The same degree of change will probably occur during the next time period. Parkinson's disease does not suddenly worsen. Unlike other conditions, like strokes or multiple sclerosis, PD has a steady, slow course without sudden dramatic changes.



E) What Medication Is Available?

It is important to understand that there is currently no cure for PD. The brain cells that have died cannot be replaced. New brain cells unfortunately do not grow to replace the old ones.

Treatment can be divided into two aspects. The first issue is, what can be done to slow the disease progression? The second is, what can be done about the symptoms of PD, the tremor, stiffness, slowness and walking problems?

No medication has been shown to delay the progression of the slowness, tremors and other problems of otherwise untreated, mild PD.

The medications for PD are all intended to improve function by partly correcting the chemical imbalance caused by the death of neurons that produce the chemical dopamine. Since none of these medications for the symptoms, such as tremor, stiffness, slowness, decreased mobility, alter the progression of the disease it is important for patients to understand that a medicine for PD should only be taken if it helps in some clear cut fashion. If a drug for the symptoms of PD doesn't improve some function then either a higher dose of the drug is required or the drug should be stopped and replaced by a different medication. Very often parkinsonians need two, three or even more drugs to treat the symptoms. And this doesn't count the medicines that might also be needed for other medical conditions.

L-DOPA is the single most important medication and is given in the form of "Sinemet". L-DOPA is a chemical normally found in the brain and is used by the brain cells to make dopamine. By giving more L-DOPA, the brain cells can make more dopamine and thus help to partly correct the diminished amount of this chemical. Unfortunately L-DOPA doesn't usually make the person completely normal and over several years, it can cause side effects (discussed below). Many doctors avoid using Sinemet when the symptoms are mild and only start it when symptoms interfere with lifestyle or job performance. Many people believe that L-DOPA stops working in five years. This is not true.

Pramipexole, Ropinerole, Rotigotine and Bromocriptine are medications that act like dopamine and are therefore helpful in overcoming problems caused by too little dopamine. Unfortunately dopamine itself cannot be given because it can't get from the blood into the brain.

Amantadine is another useful drug that appears to work by interfering with a chemical that reduces the effectiveness of dopamine. It is the only PD medicine that may reduce dyskinesias, the wiggly or fidgety movements caused by long-term use of L-DOPA.

A class of medications called "anticholinergics", act by blocking a chemical in the brain that is normally controlled by dopamine. When dopamine levels are low this chemical, acetylcholine, becomes unopposed and too strong in its action. These drugs, which include artane, cogentin, kemedrin, parsidol, akineton, act to partially block this chemical. These medications are most helpful for tremor and stiffness, and less helpful for slowness, balance and walking problems. The other drugs are helpful for all aspects of the PD, although tremor may not respond well to anything. Unfortunately these drugs have many side effects that limit their use.



F) What are the Side Effects of These Medications?

Like all drugs, these medications may produce unwanted side effects. L-DOPA can have early side effects or late side effects and will be discussed last. Since PD is a disorder of the brain, all the drugs for PD must act on the brain. Unfortunately the brain chemicals involved in PD are also involved in memory, thinking, dreaming and emotions so that occasionally people suffer medication side effects in these areas. All side effects go away when the medicine is stopped but this may take a few days.

Bromocriptine (Parlodel) Premipexole (Mirapex) Ropinerole (Requip) and Rotigotine (Neupro) can cause nausea, vomiting, lightheadedness (dizziness), especially on standing, confusion or hallucinations.

Amantadine (Symmetrel) can cause leg swelling, purple blotching of the legs, confusion or hallucinations.

The anticholinergics may cause dry mouth, constipation, memory problems, confusion and hallucinations. Since these drugs can worsen certain forms of glaucoma, an eye condition, their use may need to be discussed with an eye doctor.

L-DOPA, when first started may cause nausea, sleepiness, visual hallucinations, confusion and personality changes. One of its peculiar effects maybe to make dreams very realistic. After a few years many PD patients develop a new movement disorder called dyskinesia, in which the head, hands or feet begin to dance without the patient's control. This development is usually not a problem for the patient but occasional patients do develop problems from these movements.

Most medications help patients and do not cause side effects. It is important to be aware of potential side effects but not to be too frightened to use the medicine. All medications can cause side effects in some people. Even "sugar pills" cause side effects in some people!

G) What Can You Do for Yourself?

Learning about PD and its treatment helps you to communicate more effectively with your doctor. The medications are supposed to make the Parkinsonian feel or perform better. If a new medicine fails to do this the doctor should be notified to either increase the dose or stop the drug. Many patients don't do this and simply keep taking medicines that aren't helping. It is also important to tell the doctor about uncomfortable side effects. If side effects occur it is no one's fault and the doctor should be notified. Many patients stop their medicine without telling anyone because of side effects. On the other hand some patients experience problems caused by new medical problems and blame them on the PD or the PD medicines.

Therefore it is important to have an honest relationship with your doctor.

There are other therapies in addition to medications that also will help you function better with PD. Exercise is very important. There are two sayings that we like to use, "Rest and rust", "Use it or lose it." Walking, stretching, exercising, swimming and other activities can make you feel better. PD does make you tired so don't be afraid to rest for a short time and to space out your exercise program.

The most important thing PD patients can do now to invest in their future is to be active: physically active, socially active and mentally active.

H) How Can Local PD Organizations Help?

The American Parkinson Disease Association Information and Referral Centers would like to help. They do not provide direct services but are committed to helping you learn about PD, its treatment and local resources. Their education and support programs will make facing the challenges of PD easier.



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