



Empoderamiento Comunitario *Aware in Care Kit*

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Better Lives. Together.

La Misión del Parkinson's Foundation



El Parkinson's Foundation mejora la calidad de vida de las personas con la enfermedad de Parkinson mejorando la atención clínica y el avance de la investigación hacia una cura.

Todo lo que hacemos refleja la energía, experiencia y pasión de nuestra comunidad global del párkinson.



Cumpliendo nuestra misión



Estos pilares guían nuestro trabajo que nos permitirá tomar una enfermedad crónica, degenerativa y darle esperanza de independencia y calidad de vida a la comunidad.

La iniciativa *Aware in Care* tiene el fin de ayudar a las personas con Parkinson a obtener la mejor atención posible en el hospital.



Los hospitales son seguros ¿verdad?

Cierto o Falso

~~“Ellos nunca van a mi
neurólogo”~~

Cierto o Falso

**“La farmacia tendrá
mis medicamentos
para la P.”**



**“No todo el personal
entiende los síntomas
de la EP.”**

A large, thick, bright green checkmark is superimposed over the text, indicating that the statement is true.

**“Ellos me suministrarán
mis medicamentos a
tiempo”**

A large, thick red 'X' mark is superimposed over the text, indicating that the statement is false.

Cierto o Falso

~~“Ellos sabían los
medicamentos
contraindicados.”~~

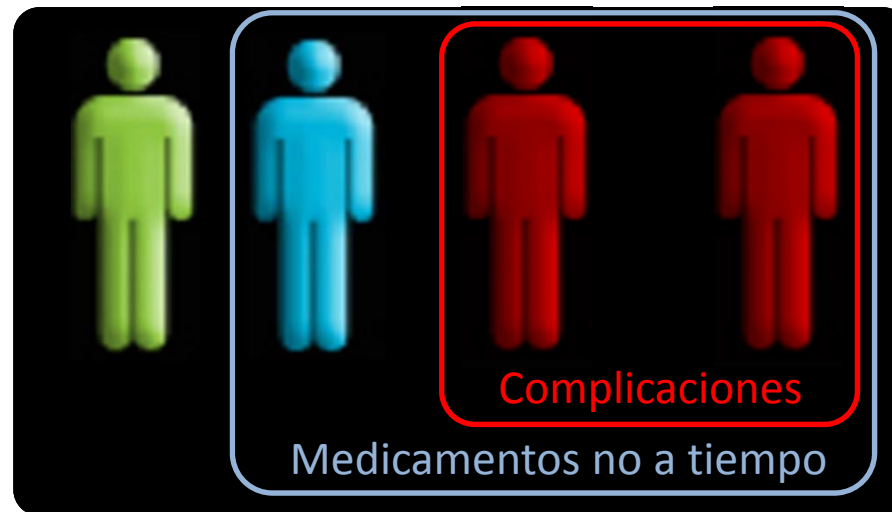
La Realidad

- Las personas con enfermedad de Parkinson son hospitalizadas 50% mas que sus pares sin Parkinson¹ y sufren complicaciones prevenibles en una proporción mas alta que pacientes no diagnosticados con Parkinson.^{1,2,3}
- Esto produce hospitalizaciones mas largas que en pacientes no diagnosticados con párkinson...^{1,3}
- ... y resulta en un riesgo de mortalidad 44% veces mas alto.^{1,3}

1. Aminoff MJ., et al. Parkinsonism and Related Disorders, 2010.
2. Derry CP, et al. Postgrad Med J., 2010. 86 (1016): 334-7
3. Guttman M, et al. Movement Disorders, 2004 19(1):49-53.

La Realidad

- 3 de cada 4 personas diagnosticadas con párkinson No reciben sus medicamentos a tiempo en el hospital.¹
- 61% de los pacientes que no recibieron sus medicamentos a tiempo, tuvieron complicaciones serias a consecuencia de esto.¹



1. KN Magdalinou, et al. Prescribing medications in Parkinson's disease (PD) patients during acute admissions to a District General Hospital. *Parkinsonism and Related Disorders*. 2007 Dec;13(8):539-40.

Por Que Ocurre Esto?

- Falta de conocimiento acerca de los riesgos de muchos medicamentos comunes para el dolor, la náusea, la depresión y la psicosis en las personas con enfermedad de Parkinson
- Las farmacias de los hospitales no almacenan la gama completa de medicamentos para la EP
- Falta de conocimiento acerca de las consecuencias del manejo incorrecto de la EP que pueden resultar en confusión mental y otros síntomas graves

El Aware in Care Kit Puede Ayudar

Parkinson's Medication Form of Awareness

Complete this form, make copies and keep them in your **Aware in Care Kit**. At the hospital, show your completed **Medication Form of Awareness** when you are asked to provide a list of medications. Fill out a new form whenever your prescriptions change and keep the updated version in your kit. **Important names and numbers:**

Time Factor: _____ Medication: _____ Pharmacy: _____
Parkinson's Doctor or Neurologist: _____ Telephone: _____
Neurology: _____
Medicine: _____
Nursing: _____

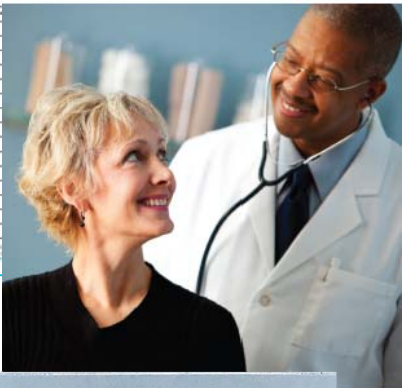
Basic Information:
I have diagnosed with Parkinson's disease in _____ (year).
I have a Deep Brain Stimulation device. Yes No
(also have the following conditions (check box))
 Constipation Depression Dysphagia
 COPD Heart Disease Osteoporosis
 Diabetes Hypertension Other _____

Medication List:
List all medications you are taking for Parkinson's and other conditions, including over-the-counter medications and supplements.

Medication	Dosage	Frequency/Time	Comments

The Parkinson's Foundation's **Aware in Care** campaign aims to help people with Parkinson's get the best care possible during a hospital stay. For more information please visit Parkinson.org/awareincare and contact us.

Aware In Care Hospital Action Plan



Parkinson's Disease Fact Sheet

About Parkinson's Disease
Parkinson's disease is a progressive, incurable neurological disorder associated with a loss of dopamine-producing cells in the brain. It is primarily associated with progressive loss of motor control, but it results in a complex array of symptoms, including many non-motor symptoms. Parkinson's impacts an estimated one million people in the United States.

Critical Clinical Care Considerations

- To avoid serious side effects, Parkinson's patients need their medications on time.
- Do not skip or postpone doses.
- Follow the exact times of day medications are to be administered so that doses given on the same schedule the patient follows at home.
- Do not substitute Parkinson's medications or stop levodopa therapy abruptly.
- Take medications immediately following procedures, unless vomiting or severely incapacitated.
- If an antipsychotic is necessary, use pimozide (Nuplazid™), quetiapine (Seroquel™) or clozapine (Clozaril™).
- Be alert for symptoms of dysphagia (trouble swallowing) and risk of pneumonia, which is seen as medically safe. Patients may require assistance.

Symptoms of Parkinson's Disease

Non-Motor

- Depression
- Anxiety
- Constipation
- Cognitive decline and dementia
- Impulse control disorders
- Orthostatic hypotension
- Risk

Motor

- Slowing or freezing of gait
- Stumbling or freezing (being stuck) or when entering or leaving a room
- Unintentional muscle contractions or stiffened speech
- Loss of facial expression
- Weakness or rigidity of the arms, legs and trunk
- Falls with balance and falls
- Hand and posture
- Reduced ability to swallow (dysphagia) and drooling

Parkinson's Medications

Medication	Dosage	Frequency/Time	Comments

MEDICAL ALERT

I have PARKINSON'S DISEASE which could make me move slowly and have difficulty standing or speaking.

I AM NOT INTOXICATED.

Please call my family or physician for help.

Parkinson's Foundation

Hello my name is _____ and I have Parkinson's disease.

Important things to remember when caring for people with Parkinson's:

- To avoid serious side effects, provide Parkinson's medications on time, every time — do not skip or postpone doses.
- Write down the exact times of day medications are to be administered so that doses are given on the same schedule the patient follows at home.
- Do not substitute Parkinson's medications.
- Do not stop levodopa therapy abruptly.
- Resume medications immediately following procedures, unless vomiting or severely incapacitated.
- If an antipsychotic is necessary, use pimozide (Nuplazid™), quetiapine (Seroquel™) or clozapine (Clozaril™).
- Be alert for symptoms of dysphagia (trouble swallowing) and risk of pneumonia.
- Anesthetize as soon as medically safe. Patients may require assistance.

The Parkinson's Foundation's **Aware in Care** campaign aims to help people with Parkinson's get the best care possible during a hospital stay. For more information please visit Parkinson.org/awareincare and call 1-800-4PD-INFO (473-4636).

Aware in Care
Parkinson's Foundation

I need my Parkinson's medications
ON TIME, EVERY TIME

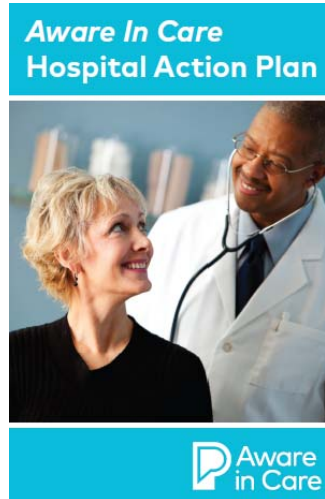
For more information please visit
Parkinson.org/awareincare or call
1-800-4PD-INFO (473-4636).



Aprendámonos sobre el Aware in Care kit!

Qué Contiene el Kit?

1. **Bulto/maletín:** Empaque el bulto con sus medicamentos para la EP y los materiales incluidos en el *Aware in Care* kit.
2. **Plan de Acción para el Hospital:** Lea acerca de como prepararse para su próxima visita al hospital; ya sea planificada o por una emergencia.
3. **Pulsera de Identificación:** Utilice su pulsera en todo momento en caso de que se presente una emergencia y no pueda comunicarse.
4. **Tarjeta de Alerta Médica:** Escriba en su tarjeta la información de contacto de emergencia y póngala en su billetera.



MEDICAL ALERT

I have **PARKINSON'S DISEASE**
which could make me move slowly and
have difficulty standing or speaking.

I AM NOT INTOXICATED.
Please call my family or physician for help.

Qué Contiene el Kit?



5. **Formulario de Medicamentos:** Complete este formulario y mantenga copias en su bulto.
6. **Hoja Informativa Sobre la Enfermedad de Parkinson C:** Comparta esta hoja informativa sobre el párkinson con el personal del hospital y pida que una copia sea añadida a su historial clínico.
7. **Hojas de Recordatorio- Yo tengo párkinson:** Comparta información vital acerca de la enfermedad de Parkinson con cada miembro de su equipo de cuidado en el hospital.
8. **Imán:** Utilice este imán para exhibir en su habitación una copia de su Formulario de Medicamentos.

Parkinson's Foundation MEDICATION FORM OF

Complete this form, make copies and keep them in your **Aware in Care Kit**. At the hospital, show your completed **Medication Form** when you are asked to provide a list of medications. Fill out a new form when your prescriptions change and keep this updated version in your kit.

Important names and numbers:

Your Name: _____ Bed Number: _____ Room No: _____

Physician Name: _____

Pharmacy Name: _____

Basic Information:

First diagnosed with Parkinson's disease in _____ (year)

Have a Deep Brain Stimulation device: Yes No

Take from the following conditions (check box):

Constipation Diabetes Headaches Urinary
 COPD Heart Disease Osteoporosis Incontinence
 Depression Hypertension Other _____

Medication List:

List all medications you are taking for Parkinson's and other conditions, including over-the-counter medications and supplements.

Medication	Dosage	Frequency/Time	Condition Treated	Started

Parkinson's Foundation Parkinson's Disease Fact Sheet

About Parkinson's Disease

Parkinson's disease is a progressive, incurable neurological disorder associated with a loss of dopamine-producing cells in the brain. It is primarily associated with progressive loss of motor control, but it results in a complex array of symptoms, including many non-motor symptoms. Parkinson's impacts an estimated one million people in the United States.

Critical Clinical Care Considerations

- To avoid serious side effects, Parkinson's patients need their medications on time, every time - do not skip or postpone doses.
- When there are any changes to your medications, they are to be administered as they were given on the same schedule, the patient follows up closely.
- Do not discontinue Parkinson's medications or stop medical therapy abruptly.
- Resume medications immediately following procedures, unless vomiting or severely incapacitated.
- If an anesthetic is necessary, use pimavanserin (Nuplazid™), quetiapine (Seroquel™) or clozapine (Clozaril™).
- Be alert for symptoms of dysphagia (trouble swallowing) and risk of pneumonia.
- Antidote is not as medically safe. Patients may require assistance.

Common Symptoms of Parkinson's Disease

Motor

- Shaking or tremor at rest
- Bradykinesia or freezing (being stuck in place when you are trying to walk)
- Low voice volume or muffled speech
- Lack of facial expression
- Stiffness or rigidity of the arms, legs or trunk
- Turbid or incontinence and falls
- Slowed posture
- Decreased ability to swallow (dysphagia) and drinking

Non-Motor

- Depression
- Anxiety
- Constipation
- Cognitive decline and dementia
- Urinary control disorders
- Obstructive sleep apnea
- Pain
- Hallucinations and psychosis
- Sleep disturbances
- Sexual dysfunction
- Urinary dysfunction

Types of Parkinson's Medications

Levodopa	Dopamine Agonists	MMA-2 Inhibitors	Anticholinergics	COMT Inhibitors	Other
levodopa (Dopamine) or levodopa (Dopamine) with carbidopa (Dopamine)	pramipexole (Mirapex®), ropinirole (Requip®), rotigotine (Neupro®), apomorphine (Xenon®), amantadine (Symmetrel®)	rasagiline (Azilect®), selegiline (Eldepryl®), saquinavel (Kylun®)	benztropine (Cogentin®), trihexyphenidyl (Serpax®), procyclidine (Procyon®)	tamoxifen (Nolvadon®), entacapone (Comtan®), opicapone (Ospan®)	anticholinergics (Benztropine, Trihexyphenidyl, Procyclidine), amantadine (Symmetrel), zinc (Zinc) or iron (Iron) supplements

Aware in Care Parkinson's Foundation

Hello my name is _____ and I have Parkinson's disease.

I need my Parkinson's medications **ON TIME, EVERY TIME**

For more information please visit Parkinson.org/awareincare or call 1-800-4PD-INFO (473-4636).

Remember when caring for people with Parkinson's, provide Parkinson's medications on time, every time - do not skip or postpone doses. Medications are to be administered so doses are given on the same schedule as they were given at home. Do not discontinue Parkinson's medications or stop medical therapy abruptly. Resume medications immediately following procedures, unless vomiting or severely incapacitated. If an anesthetic is necessary, use pimavanserin (Nuplazid™), quetiapine (Seroquel™) or clozapine (Clozaril™). Be alert for symptoms of dysphagia (trouble swallowing) and risk of pneumonia. Antidote is not as medically safe. Patients may require assistance.

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¿Que hemos aprendido hoy?

Debo utilizar el kit durante estadías hospitalarias programadas

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Debo utilizar el kit durante
visitas de emergencia

A large, thick, bright green checkmark with a black outline, positioned diagonally across the text to indicate that the statement is true.

**Debo utilizar el kit durante
visitas anuales con mi medico
de Parkinson**



Gracias !



Better Lives. Together.

