Processing a Challenging Hospital Experience Form

If you or someone close to you has PD and experienced a difficult hospital stay, use this form to help you write about what did not go well and what you want others to understand.
Once you have documented the hospital experience, form can be printed and brought to your next Parkinson's appointment or hospital stay.

PERSONAL DETAILS

Name of the Person with Parkinson's:

HOSPITALIZATION DETAILS

First Place of Care:

- ○ Urgent Care
- ○ Emergency Department
- ○ Hospital Unit (admitted directly)
- ○ Other

Did a friend or family member come with the person with Parkinson's?

○ Yes ○ No

Date of Care:

Arrival Time:

Was the person with Parkinson's transferred to a different location or facility to receive care?

○ Yes ○ No

TRANSFER DETAILS (IF APPLICABLE)

Next Place of Care:

- ○ Urgent Care
- ○ Emergency Department
- ○ Hospital Unit (admitted directly)
- ○ Other

Did a friend or family member come with the person with Parkinson's?

○ Yes ○ No

Transfer Date:

Arrival Time:

Was the person with Parkinson's transferred to a different location or facility to receive care?

○ Yes ○ No

Additional Transfer Details:

DISCHARGE DETAILS

Discharge Date:

Discharge Disposition:

- ○ Home without homecare (by themselves)
- ○ Home with homecare (with professional help
- ○ Rehabilitation in the hospital or another facility
- ○ Skilled nursing facility for long term stay
- ○ Other

MEDICATION SAFETY

Medication Errors/Safety Issues Experienced

Were Parkinson's needs discussed with anyone on the medical team? Select all that apply:

- ○ I did not receive the exact Parkinson's medications I take at home (they were substituted)
- ○ I missed multiple doses of my Parkinson's medications
- ○ My medications were given more than an hour off from my usual schedule, more than once
- ○ I received medications that made my Parkinson's symptoms worse
- ○ I did not experience any medication errors
- ○ Other

Did the medical care team explain how the person with Parkinson's medical condition or treatment might affect their Parkinson's symptoms?

- ○ Yes
- ○ No

Did the medical care team talk about whether the person with Parkinson's medical condition might have played a role in why they were admitted?

- ○ Yes
- ○ No

Medication Related Complications

Were you told that the person with Parkinson's was experiencing any of the following rare but serious reactions? Select all that apply:

- ○ A reaction to medications that block dopamine (Neuroleptic Malignant Syndrome)
- ○ A reaction to suddenly stopping or reducing Parkinson's medications (Parkinsonism-Hyperpyrexia Syndrome)
- ○ A reaction to medications that affect serotonin levels (Serotonin Syndrome)
- ○ No, I was not informed of any medication reactions
- ○ Other

Who on the medical care team brought this to your attention? List as many details as you remember.

Did the person with Parkinson's experience any of the following symptoms while in the hospital that suggest possible medication reactions experienced by the person with Parkinson's? Select all that apply:

- ○ Severe muscle stiffness (worse than usual)
- ○ High fever
- ○ Changes in heart rate or blood pressure
- ○ Confusion, hallucinations (seeing things not there) or altered mental state
- ○ Muscle spasms
- ○ Stomach problems (such as diarrhea)
- ○ Signifi ant worsening of one or more Parkinson's symptoms
- ○ No, I did not experience any of these
- ○ Other _____

New medications received (if applicable):

OTHER COMMON PARKINSON'S-RELATED COMPLICATIONS

- **FALLS: Limited mobility due to illness, injury, or missed medications can lead to falls**
- **ASPIRATION: Difficulty swallowing may cause food, liquid, or saliva to enter the airway or lungs**
- **PNEUMONIA: If bacteria enter the lungs during aspiration, it can lead to aspiration pneumonia, a serious lung infection**

MOBILITY AND FALL RELATED CONCERNS

Did you notice any changes in the person with Parkinson's ability to move? ○ Yes ○ No

Was the person with Parkinson's offered opportunities to get out of bed?

- ○ Yes, I was offered opportunities to get out of bed multiple times (more than 3)
- ○ Yes, I was offered opportunities to get out of bed, but only once or twice
- ○ No, I was not offered opportunities to get out of bed
- ○ Other _____

Did a bed alarm prevent or prohibit the person with Parkinson's from getting out of bed or moving as you/they normally would at home?

- ○ Yes, a bed alarm prevented me from moving as I normally would at home, but I still got out of bed once a day
- ○ Yes, a bed alarm prevented me from moving as I normally would at home, but I still got our of bed multiple times a day
- ○ Yes, a bed alarm prevented me from moving as I normally would at home, and I did not get out of bed for a full day or longer
- ○ No, a bed alarm did not impact my ability to move or get out of bed
- ○ Other _____

Did the medical care team explain how the person with Parkinson's medical condition or treatment might affect their Parkinson's symptoms?

○ Yes ○ No

Did the medical care team talk about whether the person with Parkinson's medical condition might have played a role in why they were admitted?

○ Yes ○ No

DYSPHAGIA AND ASPIRATION RELATED CONCERNS

Did you notice any changes in the person with Parkinson's ability to swallow?

○ Yes ○ No

Did the person with Parkinson's work with a Speech Language Pathologist/Speech Therapist on swallowing issues?

○ Yes ○ No

While you were in the hospital, did the person with Parkinson's aspirate?

○ Yes, I was told by the medical team that the person with Parkinson's aspirated
○ I believe the person with Parkinson's aspirated but no one told me that it happened
○ No, the person with Parkinson's did not aspirate

OTHER CONCERNS (IF APPLICABLE)

While in the hospital, did you or your loved one experience a different complication not listed above? If so, describe in 1-2 sentences:

FEEDBACK ON HOSPITAL CARE

Did you provide any feedback to the hospital about your or your loved one's experience?

○ Yes, I provided feedback by filling out a patient xperience questionnaire
○ Yes, I provided feedback to the medical team or the hospital's patient relations offi e
○ No, I did not provide feedback but was given the opportunity to do so
○ I was not given the opportunity to do so
○ Other _____

Is there anything else you would like to reflect about your or your loved one's hospital experience?