Parkinson's and Homecare

Parkinson's is a complex progressive neurological disease resulting from the loss of dopamine in the brain. The three primary symptoms are tremor, muscle stiffness and slowness of movement. Other symptoms include difficulties speaking or swallowing, tiredness, depression and dementia. Because it is a progressive disease, these symptoms may increase in frequency and severity over time.

It is natural for a patient (and/or their family) to want to stay at home during the early stages of Parkinson's. However, as the disease progresses there may increasing physical/mental disability and dependency which may prove very difficult for the family of the patient to meet or cope with.

These challenges may include:

- Caregivers lose the freedom to leave the home on short notice
- Time and attention is taken away from other family members, who may start to react poorly
- Because of employment or otherwise, the primary caregiver must be away from the house many hours a day
- People in the home, especially children, may need to be quieter
- Other family members or friends may offer well-meaning but inappropriate advice or, even criticism
- There is physical and emotional exhaustion from lack of continuous sleepless nights
- The physical layout of the home becomes increasingly unsuitable for even basic needs of the patient – stairs, bathrooms, fragile objects
- The patient begins to be unappreciative or even resentful of the care, which is very distressing and hurtful for family caregivers

By this time, the family (and even the patient) may start thinking about moving the Parkinson's patient to an institution, such as a long-term care facility or respite home.

There IS another option – and that is homecare.

Hiring a caregiver or team of caregivers for a Parkinson's patient has a number of important advantages.

The home environment

Most people prefer to stay in the familiar loving surroundings of their home. Being 'institutionalized' doesn't carry negative connotations for no reason. There is plenty of research that shows that patients are happier and healthier in a home environment.

Focused caregiving

Because a patient in an institution is one of many, there is always a risk of improper handling and administration of medication. This includes patients being given the wrong drugs, wrong dose, someone else's medication, or no medication at all!

It's not only the dosage and combinations of medications given that are important with medication administration; it is the timing of administering these drugs that is also key. Over time, patients may experience increasing periods when the effect of the most recent dose wears off before the next one is due and has begun to work.

An experienced home caregiver, who is specifically focusing on a single patient, is more tuned in to the patient's symptoms.

Families are in charge

One of the most frequent concerns raised by families of people with Parkinson's is that they are not listened to by institutional staff. They have a greater sensitivity to the nuances of the patient's symptoms and moods. When patients remain at

home with homecare, the family can remain the 'experts' in their loved one's lives and in being proactive with their changing symptoms.

Caregivers can cope better

While dementia, which occurs in up to 80% of Parkinson's patients, is hard for family members, it is even harder for institutional staff. An experienced caregiver in the home is close enough to the patient to understand and deal with dementia symptoms (particularly aggression) while detached enough not to take things personally.

Preparing for Homecare

If you elect to keep the progressing Parkinson's patient at home, it is important to ensure that the house is large enough to accommodate things like a wheelchair, walker, bedside toilet, etc.

All active rooms should be on one level.

Proactively, necessary modifications should be made to ensure the space is safe and comfortable (ramps at entryways, handrails, bathroom modifications, etc.).

You should meet with a case manager at a homecare company to determine how much care is required – part-time, full-time, live-in or live-out – based on the patient's specific situation. The case manager can also help determine the most appropriate kinds of additional support that the caregiver can provide – such as oversight of administration of medications, tracking of symptoms, companionship, shopping and errands, hygiene and emotional support for family and patient.

Homecare is an important consideration for the care of Parkinson’s patient to help maximize their quality of life and the lives of their loving family.