

Take care, caregivers

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Caregivers should not be ignored in the treatment of Parkinson's disease.

IN the National Parkinson Foundation Inc's *Parkinson Disease: Caring and Coping*, Chaplain Chuck Meyer of St David's Medical Center in Austin, Texas, the US, proposes a different way of looking at disease.

Conventionally, we liken managing disease to fighting a war, using phrases like "bringing in the troops" to "do battle" with drugs described as "magic bullets". Even patients whose "battles" are over are considered "at peace."

This is a very motivational approach when the war is short, or acute, and where there is still a chance the tide will turn in favour of the diseased. But what happens when the war is long and drawn out, where the disease is chronic like Parkinson's, and the inevitable outcome death? Within a warlike context, any setback, whether large or small, can only be seen as defeat and failure.

This constant win-lose scenario can be very demoralising for both patients and their caregivers. So Meyer suggests looking at managing diseases like Parkinson's as a collaboration or group project instead. One that patient, his caregiver(s), and healthcare and support workers can develop together to achieve "goals of comfort, dignity, and healing life-styles."

Managing expectations

spouses) or "wanting it all to end" *StarTwo* entertainment editor Ann Marie Chandy for example, whose late mother Sosamah (Susie) Chandy was a PWP, often wrestled with feelings of guilt and failure while caring for her with her three sisters.

"We were always asking her to do more than she was able to. She said her physiotherapist never scolded her for anything, but we always did," says Ann Marie. For example, when Susie was still able to walk, she would do so with her head bent painfully down due to muscle stiffness. Her children would tell her to look up so she could see where she was going and not bump into things. But Susie would be unable to straighten her neck.







The "scolding" came from concern that Susie would fall and hurt herself. Highly motivated and independent, Susie would insist on getting up and about - to go for walks outside, to attend church. But as her Parkinson's progressed, she fell more often, despite the presence of her daughters, a maid and numerous walking aids ("a walker with wheels, a walker without wheels, a stick, a helmet...").

Looking back, Ann Marie feels there are many things they would have done differently. She also feels that caregivers in Malaysia strongly need more support and information

STOP STARING, START CARING

Many patients with Parkinson's disease (PWP) feel doubly trapped, first by their loss of physical control and then by the cold stares and ignorance of people who do not understand their illness. We've illustrated the classic symptoms of Parkinson's disease below. How many have you seen while out and about without recognising them for what they were? Why not try to make the next PWP you meet more comfortable by offering your assistance or, at the very least, not staring rudely?

Parkinson's symptoms

				
 Stop Staring	Mild difficulty organising thoughts PWPs may find multitasking difficult and not just as a consequence of coping with their disease. Be patient, don't rush the PWP, and try to structure communication clearly.	Softer, mumbled speech PWPs may speak softer while feeling they are speaking normally. Be patient and listen. If you cannot make out what a PWP is saying, try alternative ways of communicating; ask the PWP's carer if they have personalised signals eg blinking or raising a finger to signal "yes".	Trouble swallowing, drooling Loss of facial muscle control can make swallowing difficult and even messy. Stick to the golden rule of not staring.	"Masked" or "poker-faced" appearance Loss of facial muscle control also mean facial expressions may be slow to show or appear "locked", stern, or disapproving. Don't take these faces personally.
 Stop Staring	Uncontrollable shaking, tremors in hands, arms, legs, feet or jaws when at rest When a PWP is anxious, shaking can get worse eg when they are drawing unwanted attention. Don't stare. Just accept them as part and parcel of a crowd.	Muscle stiffness, difficulty bending, "freezing up" entirely Sometimes all a PWP needs is a helping hand to get them going again eg to help pull them up from a chair, after which they can continue walking on their own.	Slow, shuffling walk Be patient and allow PWP's room to manoeuvre (especially if they're using a cane or walker). Don't jostle, push, or allow others to do so.	Stooped posture In advanced Parkinson's, muscle stiffness can result in a painfully stooped or hunched posture which they cannot straighten. Bear such limitations in mind when dealing with a PWP.

References:

1. *Living with Parkinson's at the Parkinson's Disease Foundation* (pdf.org/en/living_pd)
2. *Parkinson's Disease, Caring and Coping from the National Parkinson Foundation, Inc*

emotional healing

below are just some of the useful

matters (finances, property, busi-

In this group project strategy, it is equally important to achieve the comfort, dignity and healing of the caregiver as that of the patient. This is because the person with Parkinson's (PWP) will most likely have his expectations managed by his specialists (neurologists, nutritionists, psychiatrists, physiotherapists), but his caregiver may not.

In caring for their PWP, it is common for caregivers to feel:

- Inadequate and guilty for not being able to do more
- Frustrated, angry and worn out when faced with setbacks or the negative attitude of their PWP (who may be struggling with guilt, frustration and depression of his own)
- Shocked and horrified about having thoughts of leaving their PWP (especially if they are their

on how to care for their PWPs while caring for themselves too.

Caregivers need care too

It is normal for caregivers to feel lost and uncared for while providing so much care for their PWPs.

The first thing caregivers need to accept in order to have a positive relationship with their PWPs is they cannot heal them physically. Their PWPs will not be cured by care and attention, as there is currently no cure for Parkinson's disease, and the severity of the condition will worsen over time despite their best efforts.

If you are a caregiver, don't feel demoralised about what you cannot change. Focus instead on what you can by providing physical comfort, loving support, stimulation, and

emotional healing.

Secondly, it is important for caregivers to schedule "me" time in which they can have a life away outside Parkinson's and de-stress, eg by spending time on a hobby or going out with friends, and to not be too hard on themselves.

Thirdly, it is ok for caregivers to need – and ask for – support too. This can be as simple as having a friendly chat or "unloading" session with someone close when you're down, or as profound as setting up your own local support group amongst other PWPs and caregivers you know in your area.

Find out more

Most of the information on coping with Parkinson's disease available locally is patient-centric. Listed

below are just some of the useful resources available online written with caregivers in mind.

For gentle encouragement on coping as a caregiver, visit the Michael J. Fox Foundation for Parkinson's Disease Research at www.michaeljfox.org/living.cfm. Click on "For Patients and Caregivers" then click on "Guide for Caregivers" on the left navigation bar.

For a free e-copy of *Parkinson's Disease: Caring and Coping*, visit www.parkinson.org. Click on "Publications" at the top navigation bar, and look under "Education Manuals" for "Caring and Coping". This is a thorough guide for caregivers and PWPs on how to manage expectations, develop disease management action plans, sort out legal

matters (finances, property, business), and living tips.

For more practical living tips with sections titled *Especially for carepartners* and lists of special equipment for PWPs, follow the same steps as for *Caring and Coping* and click instead on "Activities of Daily Living".

For formal support, general information, inspiring true life stories and to get in contact with other PWPs and caregivers, contact the:

- Malaysian Parkinson's Disease Association in Happy Garden, KL (03-7980 6685; www.mdpa.org.my)
- Negeri Sembilan Parkinson's Association in Seremban (06-763 6275 / 06-764 4177; www.nsmmps-parkinson.org) – **By Lee Tse Ling**

See SF4 – Back to the past