

## UNIT NO. 6

# MANAGING THE CAREGIVER FROM THE GENERAL PRACTITIONER'S (GP'S) PERSPECTIVE

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**ABSTRACT**

**Support for caregivers has been proven to reduce caregiver depression, burden of care, and improve their health and quality of life. Caregiver support also benefits the care outcomes of the dementia patient. There is a need to recognize that caregivers too need caring. Caregivers of dementia patients are usually middle-aged daughters and sons followed by spouses. Foreign domestic helpers also are often the caregivers. Stressors from caregiving change at different stages of the disease. As the disease progresses, stress from having to deal with behavioural problems diminishes as stress from having to deal with functional impairments increases. Information given must be stage specific to be useful to caregivers. Work towards giving a positive experience in the GP consultation: early diagnosis, stage specific information, up-to-date information on sources of help.**

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**INTRODUCTION**

Caregivers are an integral part of the support and care of the dementia patient. Support for caregivers has been proven to reduce caregiver depression, burden of care and improve their health and quality of life.

More importantly, it also impacts on dementia patients' care, quality of life, behavioural changes, medication compliance and rates of institutionalisation. Many studies have consistently shown this. In the case of dementia patients, there often two tenets espoused: (1) Treatment has to embrace both pharmacological and non-pharmacological methods (2) Treat the patient, treat the caregiver.

The importance of caregivers cannot be over-emphasised. In Singapore, based on the findings from a study conducted by Alzheimer's Disease International in Asia Pacific<sup>1</sup>, the prevalence of dementia in 2020 and 2050 will be close to 53,000 and 187,000 respectively. Taking into account the caregiver, this means that an additional 53,000 and 187,000 caregivers and/or families being affected as well.

It is paramount in dementia care not to neglect the caregiver. He/she is often the silent patient or sufferer. Caregivers too need caring. Managing or rather caring for them includes: (1) continual assessment of their needs, (2) support in the form of education, empowerment and enablement, (3) Helping them to look after their own health.

In ageing Singapore, General Practitioners (GPs) will play an increasing role in meeting the healthcare needs of the silver generation. In addition, care of dementia patients and caregivers by GPs will gain increasing importance in light of the fact that there are too many patients and insufficient specialists to meet this need.

Can GPs make a difference to the patient and caregiver(s)? The answer is yes, of course! Patients and caregivers do listen to their GPs and what GPs say and/or do impacts on them mentally, emotionally, spiritually. A study by Fortinsky<sup>2</sup> showed that when symptoms of dementia emerge, patients and caregivers turn first to their primary care physician for answers to questions about memory loss and obtaining a diagnosis. Clearly, GPs have and will have a pivotal role in contributing to the management of dementia patients and support of caregivers in the years to come.

**CAREGIVERS**

Local studies have shown that the majority of caregivers are women<sup>3,4,5</sup>. Caregivers are usually middle-aged and mostly children followed by spouses<sup>4,5</sup>. Many of caregivers rely on other family members for additional help. About half hold a full-time or part time job<sup>3</sup>. In the Chinese family, there is also a hierarchy of expectation that the relative will be a caregiver in the order of: spouse, daughter, daughter-in-law, son and other kin<sup>3</sup>. As a reflection of changing social norms and disintegration of the extended family, quite often it is usually the unmarried daughter or son who is left to care for the older patient. Other caregivers include friends, volunteers and home nursing aides.

Besides family members, most families engage the help of a foreign domestic helper (usually from Philippines, Indonesia or Myanmar). This has led to a dichotomy of caregiving tasks. The foreign domestic helper does the physical caregiving while the children provide financial support and make the decisions regarding medical care, place of stay, etc. In large families, it is not uncommon for the patient and foreign domestic helper to rotate and stay in the individual children's homes for certain periods of time. For smaller families, it is also not uncommon for the foreign domestic helper to stay with the patient in a one or two room Housing Development Board (HDB) flat. It is thus important to look into the needs and burdens of this group of helpers as they assume the role of the main caregiver for their patients and quite often are more aware of cognitive and behavioural changes in the patient during the course of the illness.

Factors that affect caregiver performance

Characteristics that influence caregiver performance include: age, gender, healthcare status, kin relationship and racial/ethnic background (Table 1)<sup>6</sup>. Older spouses have more caregiver stress and burden as they themselves are often beset with ill-health or even become cognitively impaired themselves. Women and wives tend to have more psychological stress in caregiving<sup>7,8</sup>. The relationship to the patient is also important. Daughters-in-law who have a difficult relationship with their mothers-in-law often have more caregiver stress<sup>3</sup>. With regards to ethnicity and caregiving, not much is known locally; although Malay families appear more willing to take up caregiving roles for their demented relative.

Table 1. Characteristics that influence caregiver performance<sup>6</sup>

- Age.
- Gender.
- Healthcare status.
- Kin relationship.
- Racial/ethnic background.

Stressors from caregiving

As dementia progresses, caregivers experience greater suffering compared to the patients (Table 2). A local study<sup>4</sup> done in 1999 on the burden of caregiving in mild to moderate dementia, even in the earlier stages of dementia, 48% of caregivers reported the caring process to be a difficult one. More importantly, these difficulties were serious enough to be significantly associated with institutionalization plans for the patient. In this group, behavioural problems featured more prominently than functional disabilities in association with the caregiver's problematic status. This pattern was reversed in an earlier study<sup>10</sup> done on severely demented patients. Clearly these two studies suggest that when dementia advances, as behavioural problems tend to diminish in intensity and functional impairments become more pronounced, caregivers encounter different sets of problems at different stages of the disease.

Another common observation is that of patient resistance. Quite often in our local setting, patients are resistant to receiving help from a family caregiver or a foreign domestic helper for variety of reasons, including: strained/distant relationships, existing personality traits that become more pronounced or altered or new ones emerge during the dementing process, language barriers, perception/delusion of being persecuted or harmed by the caregiver, feeling of abandonment especially for those who retain some insight in the earlier stages of disease.

The closeness of the relationship between the patient and understanding of the patient's background, personality, previous occupation(s), likes and dislikes plays a crucial role in helping the caregiver understand the reasons behind the patient's behaviour. Often, behavioural and personality issues may seem bizarre but with careful understanding and anticipation of the behaviour, behaviours can often be modified and thus become less stressful for the caregiver.

The impact of caregiving on the caregiver can also be felt in indirect ways (Table 3). Caregivers are often torn between the needs of the patient and that of their nuclear families. Most have restricted social lives and have less time for vacations, hobbies, social or religious groups. This can lead to much strain and conflict within families. Caregiver burnout is thus common and needs to be looked into regularly (Table 4).

Impact of caregiving on Caregivers

The impact of caregiving on the caregivers can be divided into 4 categories:

(1) Impact on Emotional Well-Being

In a previous study on Chinese families of dementia patients in Singapore, behavioural symptoms were significantly related to caregiver stress. Overseas studies also paint a similar picture, more than 40% of family and other unpaid caregivers of people with Alzheimer's and other dementias rate the emotional stress of caregiving as high or very high. Up to one-third of family caregivers overseas have symptoms of depression. In the local study of mild to moderate dementia, 47% of caregivers who had caregiving problems experienced significant depression. Even amongst caregivers without problems, 13% had significant depression.

The notion that nursing home placement would bring relief of stress may actually not the case in some families. One study found that family caregiver stress and depression were just as high after the placement as before placement.

Table 2. Stressors arising directly from the caregiving situation<sup>9</sup>

- Degree of patient's cognitive problems.
- Functional ability of patient.
- Degree of problematic behaviour.
- Degree of patient resistance.

Table 3. Stressors arising indirectly from the caregiving situation<sup>9</sup>

- Constriction of social life/leisure time.
- Work strain.
- Financial strain.
- Family conflict.

Table 4. Factors associated with caregiver burnout<sup>6</sup>

- Feeling overwhelmed, angry or frustrated by caregiving responsibilities.
- Feeling frustration or angry with care recipient.
- Feeling that life or health has suffered since becoming a caregiver.
- Feeling that you are not doing a good job.
- Feeling that your efforts do not matter or are futile.

## (2) Impact on the Caregiver's health

In a local study<sup>3</sup> involving 50 family caregivers of Chinese dementia patients, 56% had poorer general health based on the General Health Questionnaire (GHQ) that correlated significantly with incontinence, delusion, hallucination, agitation, sleep disturbance and depression in the patient.

Caregivers of dementia patients are more likely than non-caregivers to report their health to be fair or poor<sup>11,12</sup>.

Caregivers are also more likely than non-caregivers to have high levels of stress hormones<sup>12,13,14,15</sup>, reduced immune function<sup>12,16</sup>, slow wound healing<sup>17</sup>, new hypertension<sup>18</sup> and new coronary heart disease<sup>19</sup>. The impact on health can also be demonstrated at the chromosomal level: caregivers of Alzheimer's disease patients have significantly shorter telomeres on average than other people of the same age and gender<sup>20</sup>.

## (3) Impact on the Caregiver's employment

Many caregivers often have to reduce working hours or quit work or take time off because of caregiving responsibilities. One study found that 57% of caregivers were employed full time or part time. Of those employed, two-thirds had to go in late, leave early or take time off because of caregiving; 18% had to take leave of absence; 13% had reduced hours; and 8% turned down promotions<sup>21</sup>. Clearly, lost of income and employment adds to the caregiver burden as well.

## (4) Impact on Caregivers' income and financial security

Locally, many caregivers exhaust their finances including their medisave accounts in providing care for the dementia patient throughout the stages of disease. Besides food and basic necessities, other out-of-pocket expenses include medications for dementia, day care, foreign domestic helper employment, transport, rent, nursing home costs, home medical and/or nursing, ancillary services such meals on wheels, laundry etc. Financial insecurity inevitably adds to the caregiver burden.

## Positive aspects of caregiving

The positive aspects of caregiving are often overlooked. Physicians can help the caregivers identify and emphasise the positive aspects of caregiving<sup>6</sup>. Cohen found that 73% of her subjects could state at least one positive aspect of caregiving<sup>22</sup>. A local study on caregiving gains identified 3 areas of gains: (1) Personal growth (2) Gains in relationship and (3) Higher level gains<sup>23</sup>. Caregivers can derive intrapersonal satisfaction, meaning in caregiving and feel good knowing their actions can promote positive situations and avoid negative ones<sup>24</sup>. They also gain new perspectives and sense of purpose in life. The degree of meaningfulness in caregiving was also correlated with the presence of depression in a study by Noonan and Tennstedt<sup>25</sup>.

GPs can certainly help the caregiver identify healthy, positive

aspects of caregiving. This will boost morale of caregivers and also provide opportunities for the GPs to detect low moods, burnout and depression<sup>9</sup> amongst caregivers especially when they are persistently pessimistic and unable to identify any positive aspects of caregiving.

## CAREGIVERS' EXPERIENCES WITH GPs

Caregivers have mixed experiences with GPs. A positive experience can bring about earlier detection and diagnosis of dementia, appropriate early intervention, reduction of caregiver stress and contribute to the overall holistic care of patient and caregiver alike. A negative experience often brings much frustration and stress on the part of caregivers besides delay in diagnosis and treatment.

A small novel study done on GPs in Australia in 2008 focussed on patients' and caregivers' experiences with GPs in settings where GPs provide a wide range of services in the absence of dementia specialist services<sup>26</sup>. The themes explored included: diagnosis, cognitive testing, dementia knowledge, carer support, treatment, medication compliance. Below are some of the findings.

### Diagnosis

Twenty-five percent (5/20) respondents reported prompt diagnosis by their GPs. The rest had delays of 1-8 year intervals between onset of symptoms and diagnosis. Three patients were aware something was wrong but only one was offered investigations. Two were frustrated when diagnosis was initially refuted by their GPs.

### Dementia Knowledge

Of the 4 respondents, two had positive comments on their GPs' ability to offer prompt diagnosis and access to support. Two had negative comments which attributed difficulties in accessing help to GPs' lack of knowledge about dementia.

### Carer support

The interviews focused on carer support, discussing relief from help received and the frustration of being unable to access help. Many positive comments demonstrated that the most reliable, up-to-date source of information about dementia support services came from other carers who had firsthand knowledge of pitfalls and benefits, and not from the GP. A quarter (n=5) of the interviews produced negative comments about the services received, demonstrating the strong recall and impact of negative experiences.

*'Not a damned thing happened for us. That was the hard part because she had no help. You didn't know what help there was.'*  
(A daughter)

## Medication compliance

Medication compliance was an issue in nearly half the cases (n=9). This was a major problem when the patient was self caring.

This study showed that the diagnosis of dementia may often be missed in routine consultations. More importantly it also showed that patients at early stages may be aware of their own dementia and the importance of listening to them. With regards to dementia knowledge, *"most patients trusted their GPs to be informed about the disease and deficiencies in knowledge delayed diagnosis and led to less optimal support and management."*.....*"Negative comments were also received when GPs failed to identify the disease or arrange for support."* *"Caregivers appreciated a diagnosis that explained what was happening, even when prognosis was difficult."* For carer support, "patients and caregivers expected their GP to offer appropriate care and access to dementia support but others to be better informed about support services." It also showed that many older persons (and caregivers) valued a GP who could inform them.

Locally, some may have similar experiences with their GPs and reinforces the view that GPs are well placed to initiate early support, diagnosis, treatment and reduce caregiver stress and burden. In addition, medication compliance is a big issue with dementia patients and carers need to be encouraged and supported to take active part in the organisation and supervision of medication taking.

## OPTIMAL CARE AND THE HEALTH CARE TRIAD

In Singapore today, GPs have a great wealth of resources available to draw from and help in supportive care to patients and families. Against a primary care setting of limited time, changing symptoms with disease progression, possible negative attitude towards dementia diagnosis and treatment, inadequate reimbursement and lack of incentive for quality follow-up the interactions between the GP, patient and caregiver(s) are most critical for optimal dementia care and support. A review by Holmes and Adler<sup>27</sup> sounded out a few pointers that enhanced this interaction. These include (1) being alert to cognitive and behavioural changes in the patient (eg. missed appointments, non-compliance with medications, frequent telephone calls to the clinic, missed payments and a family member accompanying the patient to the clinic visit when there was none before), (2) involving the patients in their own care, (3) identification of a principal caregiver, (4) progressive involvement of the caregivers in the care plan as the disease progresses. The relationship of the GP with the patient and caregiver thus forms a critical "health care triad"<sup>2,28</sup> which is essential for optimal dementia care and management<sup>29</sup>.

## MANAGEMENT AND SUPPORT OF CAREGIVER

### *When and how?*

The needs of patients and CG change throughout the course of the dementing illness, this means that support and interventions for the caregiver would also be different at various stages of dementia. The following lists important interaction (hence, intervention) points between the GP and caregiver.

### Critical stages of interaction and support:

- (1) Diagnosis and disclosure
- (2) Early stage disease
- (3) Middle stage disease
- (4) Final (late) stage disease
- (5) Bereavement
- (6) Referral and use of community resources

### **(1) Diagnosis & Disclosure**

Patients and families/caregivers want an accurate and clearly explained diagnosis and guidance from their physician in understanding the course of illness over time<sup>30</sup>. "Specifically, caregivers want their physicians to listen to their concerns, devote more time to discussing diagnosis and what it means, and include the patient even if he or she might not fully understand."<sup>30</sup> Research has documented that these factors are closely linked to with caregiver satisfaction<sup>6</sup>.

Depending on the patient and caregiver, the disclosure process should be tailored to suit patient and family, e.g. direct approach (come straight out and tell) or softer approach<sup>30</sup>. While most physicians and caregivers prefer to focus on discussions on memory problems, safety issues, behavioural issues (which impact on the patient's care) rather than the term Alzheimer's disease; most families would also eventually want more specific information regarding the diagnosis and prognosis<sup>30</sup>.

### **(2) Early stage disease**

Accepting and learning the role of a caregiver is the primary goal for most caregivers at this stage<sup>6</sup>. Caregivers are usually under stress or denial during this stage and are often fearful of grappling with the unknown. Time taken to educate and empower the caregiver certainly helps the caregiver to cope better and reduce caregiver burden. Simple explanations with written materials, brochures, books on caregiving and information on caregiving websites are ideal. Repetition of important information (that are likely to be forgotten) over several visits would also be helpful to caregivers. Referrals to caregiver support programmes would also be a good way for caregivers to seek additional support and advice (Table 5).

Other care plans that can established with the caregiver at this stage<sup>6</sup> include:

- Adaptation
- Financial, legal planning and advance directives
- Establishment of support system for the caregiver



**Table 5. Caregiver support programmes**

1.	Alexandra Hospital Geriatric Centre	378 Alexandra Road, Singapore 159964	Tel: 6379 3420 Fax: 6471 4508
2.	Alzheimer's Disease Association	Blk 157 #01-1195, Lorong 1 Toa Payoh, Singapore 310157 Fax: 6353 8518	Tel: 6353 8734
3.	AWWA Centre for Caregivers	3rd Level, ACCESS Building, 11 Jalan Napiri, Singapore 547532 Fax: 6511 5319	Tel: 6511 5318
4.	O'Joy Care Services	Blk 5 #02-10, Upper Boon Keng Rd, Singapore 380005 Fax: 6742 1909	Tel: 6749 0190
5.	St Luke's Hospital (Care Connect @SLH)	2 Bukit Batok St 11, Singapore 659674	Tel: 6563 2281 Fax: 6564 9557

### Adaptation

Becoming a caregiver is often unplanned, life-changing and a long term event. Spouses or children have to discard old roles and take on new roles, e.g. from being the son to becoming the carer and decision maker for the father. Emotional support & empathy crucial at this stage.

### Financial, legal planning and advance directives

Advice should also be given to the patient and caregiver on sorting out financial issues such as bills, bank accounts, automated teller machine (ATM) numbers, insurance, Central Provident Fund (CPF)/Medisave accounts etc. With the passage of the Mental Capacity Act (Singapore) in 2008, patients can assign health care decision making designees (known as donees). Other considerations include advance medical directives, will and estate planning.

### Establishment of support system for the caregiver

Helping the caregiver to look after him/herself is also important. GPs can play a role in involving extended family members and friends in caregiving so as to relieve the burden on the primary caregiver(s). Besides caregiver support groups, caregivers can be encouraged to seek support through religious or voluntary groups and even neighbours.

### **(3) Middle stage disease**

This stage is characterized by the emergence of behavioural/ personality changes in addition to progressive cognitive and functional decline. Most caregivers face significant burden and need significantly more help at this stage. However, most caregivers are faced with the difficulty of recognizing they need more help at this stage<sup>6</sup>. In addition, accepting help is often more difficult than recognizing the need for more help. In the local study<sup>3</sup> on caregivers, Chinese caregivers relied more on family support and less on psychogeriatric services for fear of 'losing face'; though this view may be slowly changing with decreasing size of nuclear families. For some caregivers, finding and negotiating for help can be as daunting as the caregiver burden. Quite often, caregivers often delay seeking help till a crisis or burnout occurs.

GPs are well placed to help out. Look out for caregiver distress, depression, frustration and burnout (Table 4). Actively ask and enquire about the state of the family and/or domestic helper. A major turning point in the care needs occurs when the patient requires round the clock care. Often, families have to re-organise their care plan, involve more family members, hire a new helper or consider nursing home placement. The ability of the caregiver to cope may often depends on the amount and quality of formal and informal support<sup>3</sup>. Consider early referral to appropriate resources, caregiver support groups (if they are not part of one already), referral for respite in nursing homes, dementia day care, home help services etc. Regular contact with the specialist-in-charge (if available) for more help and advice would improve care of the patient and caregiver.

### **(4) Late stage disease**

At this stage, patients are often debilitated and dependent on others for the activities of daily living. Behavioural and psychological changes are also on the wane and may be markedly reduced. Caregivers are faced with decision making and preparation for various end-of-life issues and trust their physician to help them make difficult choices. These include do-not-resuscitate orders, feeding issues (including decisions on naso-gastric tube feeding), minimization of medications, comfort care etc.

Advance planning would also help the caregiver tackle these issues early. When appropriate, early referral should be made to home medical care, hospice care and nursing home placement.

### **(5) Bereavement**

Bereavement on the part of the family/caregiver begins from the sense of loss of the loved one's personhood while the patient is still alive. Depression highly prevalent especially among those who experience loss of companionship and relationship<sup>6</sup>. Even after death, though there is closure, caregivers can still have grief reactions up to 3 years after death<sup>9</sup>. Hence, GPs are well placed to look out for this and provide counsel and support for the caregiver.

## (6) Referral and use of community resources

Besides information from hospital-based clinics, the websites of Alzheimer's Disease Association of Singapore (alzheimers.org.sg) and the Agency for Integrated Care (ww.aic.sg) provide much information of community resources and services. ADA has also a list of community resources for dementia that are available for GPs.

## ADDITIONAL TIPS IN MANAGING THE CAREGIVER

- Establish contact and touch base with the specialist to gain greater understanding of the patient's and caregiver's needs.
- Understand the background history and personality of the patient. This is part of patient-centred care<sup>31</sup>. Oftentimes one can understand the reason behind certain behavioural changes or patterns once these are taken into account, this will help the caregiver achieve greater understanding of the patient, cope better and reduce caregiver stress.
- Actively identify correct problem e.g. wandering, agitation, family conflicts over care issues, conflicting expenses, medication compliance etc.
- Give stage specific information; divide important information into bite-sized portions over several visits.
- Listen to the caregiver during the office visit and allow time for him/her to ventilate; this may be most helpful and revealing and direct the course of intervention.
- If the spouse is the main caregiver, enquire about the cognitive status of him/her and get him/her assessed as necessary. This is because cognitive decline in the elderly caregiver can often be missed and may also be the cause of caregiver problems as well.

## SUMMARY AND CONCLUSION

With the ageing population, GPs are often the first ones who can detect the presence of cognitive decline against a setting of other chronic medical conditions. They are also the first ones to whom patients and caregivers turn to for advice and help. With greater awareness and earlier detection, there is much that the GP can do. Support and care for the caregivers by GPs will definitely help caregivers who are often the silent 'patient' or 'sufferer'. This will enable more holistic care for the patient and caregiver and greater GP satisfaction in the management.

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### LEARNING POINTS

- **Support for caregivers has been proven to reduce caregiver depression, burden of care, and improve their health and quality of life.**
  - **Caregivers of dementia patients are usually middle-aged daughters and sons, followed by spouses. Foreign domestic helpers also are often the caregivers.**
  - **As the disease progresses, stress from having to deal with behavioural problems diminishes as stress from having to deal with functional impairments increases.**
  - **Information given must be stage specific to be useful to caregivers.**
  - **Work towards giving a positive experience in the GP consultation.**
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