

## UNIT NO. 3

**HOW DO GENERAL PRACTITIONERS FOSTER MUTUAL SUPPORT WITH FAMILY CAREGIVERS IN OPTIMISING HEALTHCARE FOR PERSONS WITH DISABILITIES?**

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**ABSTRACT**

**The number of persons with disabilities (PWD) that GPs will attend to will increase due to the rapid ageing population and increasing life expectancy in Singapore. It is important for GPs to work in partnership with family caregivers in order to optimise the healthcare of all PWD, including those with congenital and acquired disabilities. This paper examines the challenges and needs of caregivers; and suggests ways for GPs, caregivers and government to enhance the healthcare experience of PWD.**

**Keywords:**

**Care Triad, Caregiver Stress, Caregiver Support.**

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**INTRODUCTION**

Based on service utilisation and recent national health survey, the estimated number of persons with disabilities (congenital and acquired) was 97,200 or 3% of the resident population in 2010<sup>1</sup>. Currently, there is no official central registry of persons with disabilities (PWD). With the rapid ageing population and the increasing life expectancy in Singapore, the number of older persons with acquired disabilities will increase. PWD, just like the rest of the population, have their primary health care needs met by outpatient polyclinics and private medical practitioners' clinics. Though the population of PWD is small, it is believed that many general practitioners (GPs) would have treated a PWD before and that they will be seeing more patients with disabilities in future based on the increasing prevalence rate.

Very often, in the course of providing primary health care to PWD, GPs have to work with caregivers closely in order to optimise the medical care of PWD. It is imperative for GPs to support caregivers in their care for the PWD, so that they in turn can support GPs in their provision of healthcare to PWD in an effective manner. This kind of mutual support between members of care triad (GP, caregiver and PWD) will help to prevent relapse, delay revisits and achieve positive healthcare outcomes for PWD.

**IDENTIFYING FAMILY CAREGIVERS**

In order to cultivate strong mutual support with family caregivers, it is important for GPs to identify them as partners and understand their roles as caregivers. The term "caregivers" as used in this paper refers to unpaid family members, relatives or friends who primarily look into the physical, health, financial, social, emotional and spiritual needs<sup>2</sup> of PWD and related legal issues involved; while providing support to meet most or some of the needs, while seeking help from others to meet the rest of the needs. Some families have only one main caregiver; some may have more

than one caregiver; and some caregivers receive help from others for care and ad-hoc support. Sometimes, GPs have to also work with other care members of the PWD such as professional caregivers and domestic helpers.

**UNDERSTANDING CAREGIVERS' CHALLENGES & NEEDS**

Caregivers face challenges such as taking on many roles and performing many tasks, and most of them are unprepared to provide care, have limited or no knowledge to deliver proper care, receive little guidance from healthcare professionals and limited support from others<sup>3</sup>. Regardless of the type of disability their charge has and number of years in caregiving, caregivers may experience stress at any point of the journey. This could occur due to change in the medical or behavioural conditions of the PWD, family discord over care, imbalance between caregiver's work, family and caregiving, financial stress, or worries over the future of their charge especially after they have passed on. Caregivers often have to deal with negative feelings like frustration, anger, guilt and despair.

Challenges arise throughout the four stages of a caregiving journey. During the beginning stage, also called the "questioning" stage, caregivers struggle to accept the loss of ability of their loved one and understand the medical conditions, diagnosis and prognosis. Some of them may be in a state of denial or anger, questioning why things have turned out the way they have. Most caregivers in this stage feel lost and hopeless. When caregivers eventually move on to the "acceptance" stage, they will be challenged by the many care tasks to perform, with more social and health care agencies to coordinate with. They have to juggle between work, family, leisure and caregiving. Very often, they have to put on hold their own plans for their charge. When situation stabilises somewhat and caregivers become more familiar with their caregiving role and resources available, they would have reached the "established" stage. They may start to think about the future of their charge and try to anticipate all possible future plans, and hold family meetings to share the care and plan ahead. It is understandable that caregivers will never stop worrying about their charge's future. An especially worrisome aspect for the lone caregiver is contemplating the thought of their own passing before their charges. In the last stage of a caregiving journey, caregivers prepare to learn how to "let go and move on". This will be the stage where caregivers learn to let go of guilt and worry after having done whatever was possible for their loved one/ charge. This may also be the time for grief when their charge has passed on.

Studies<sup>4,5,6</sup> have found caregivers are likely to be in distress if they:

- provide more than 21 hours of care per week;
- experience physical stress;
- juggle with work, family, leisure and caregiving;
- are economically disadvantaged;

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- have poor coping skills;
- have low education level;
- have minimal support network;

and their charge has:

- moderate to severe cognitive impairment;
- aggressive behaviour;
- impairment in instrumental activities of daily living;
- symptoms of depression.

Caregiving may have both positive and negative impacts on caregivers. Positive aspects include nurturing stronger family ties, developing meaningful relationship with care triad members and care recipients, discovering new areas of personal growth, and feeling competent and empowered as a result of the caregiving experience. However, negative impacts are many as well, and need to be recognised and dealt with. Caregivers who under-prioritise self-care may expose themselves to the risks of burnout, depression and other stress-related illnesses which impact their overall health and undermine the quality of care they deliver to their charges. In Singapore, it was estimated that 30% of elder abuse cases occurring annually were due to caregivers' stress<sup>7</sup>. In extreme cases, caregivers have been driven to attempt suicide and homicide<sup>8</sup>.

Caregivers' needs are usually "invisible" to the families', health workers', agencies', society's and policy makers' attention. GPs are important touchpoints to identify caregivers' stress and help them cope before the caregiver is overwhelmed into desperate actions. For example, GPs can help improve the experience of caregivers of PWD. Studies show that GPs are well-placed persons to guide caregivers in need of information and support<sup>9</sup>. Very often, caregivers do not know when they need community resources, or how to access and utilize them. They require not only physical help but also training, psycho-education and emotional support<sup>3</sup>. Support for caregivers can help alleviate the burden of care, improve health and quality of care/ life, and reduce burnout and depression<sup>10</sup>.

### **FACTORS AFFECTING THE CAREGIVERS' EXPERIENCE WITH GPs**

A study by Greenwood, Mackenzie, Habibi, Atkins and Jones<sup>11</sup> found that most GPs recognised the need to support PWD and caregivers but felt that they lack time, resources and training in doing so. Another study by Schoenmakers, Buntinx and Delepeire<sup>12</sup> found that caregivers felt GPs lacked appropriate communication skills, were unaware of their worries and feelings of grief and distress, and failed fully to take their perspective into account. Others studies have identified communication as a common barrier<sup>13,14,15</sup>.

There are many other factors affecting caregivers' perceptions of weak support received from GPs. This includes the tendency to stereotype, negative attitude, lack of commitment and cultural sensitivity, GPs' limited knowledge of disabilities, limited time spent per visit, lack of expressed empathy, and management policies (e.g. protocol in handling patients with disabilities).

There are dilemmas GPs face in seeking to provide support to caregivers. First, there is limited support they can offer caregivers due to pressure of time, especially in busy clinics. They will not be able to identify caregivers' stress if caregivers do not bring it up with their GPs. Second, there are also issues of confidentiality and autonomy, when caregivers do not allow space for patient-physician communication, patients and caregivers do not have shared interest, or whether patients are able to make decisions. Some studies have found that patients with mild to moderate cognitive impairment are able to make valid statements of wishes, values and preferences<sup>16,17</sup>. Third, whether GPs should bill caregivers when they tag along with patients and seek a medical opinion for their own ailments. These dilemmas may put GPs in difficult positions when they try to develop positive partnerships with caregivers.

### **FOSTERING SUPPORTIVE RELATIONSHIP BETWEEN MEMBERS OF THE CARE TRIAD**

In order to foster supportive relationship with caregivers, GPs can do much to support caregivers and elicit support of caregivers to support them (GPs) as well, in the mutual interest of delivering effective and efficient healthcare to PWD.

#### **Things GPs can do:**

- Treat PWD as individuals with unique needs rather than as "disabled" persons. Speak directly to them when they are able to communicate before seeking additional information from caregivers.
- Engage caregivers as part of the healthcare team and make use of their care expertise.
- Prepare caregivers in advance by discussing patient's treatment plans over life course, and allow time to discuss diagnosis and care arrangements.
- Ensure a common and accurate understanding of medical instructions when communicating with caregivers<sup>14</sup>. Minimise medical jargon; provide written instructions and pamphlets on medical conditions for reference.
- Follow-up with calls to check compliance.
- Assess caregivers' wellbeing, pick up signs of burnout and promote caregiver self-care.
- Show understanding of caregivers' challenges and speak with empathy.
- Use supportive and non-judgemental communication; choose positive or neutral words when discussing care and avoid negative ones like burden or suffering.
- Sign-post caregivers to community services for PWD and for caregivers, and help them understand the role of such additional services in improving their quality of care/ life.
- Equip yourselves with knowledge about disabilities and community resources, build networks with care specialists and community service providers.
- Consider shorter wait time or separate waiting room where possible for PWD such as those with autism spectrum disorder or attention-deficit hyperactivity disorder.

#### **Things GPs can advise caregivers to do:**

- Prepare their charge for doctor/dental visit through role-play, books, and pictures.

- Note down the medical history and their questions in point form before visits if they need time to organise thoughts/information.
- Call before visits, prepare staff ahead of time, and remind them of the needs of their charge.
- Schedule either the first or last appointment (if applicable) for shorter wait time or a less crowded waiting room.
- Bring distractions to engage their charges at the waiting room and exam room.
- Act as one point of communication instead of sending different people to accompany their charge for medical appointments each time.
- Bring a support person if they have difficulty in understanding medical conditions and care instructions.
- Have separate consultation time for their charge and themselves.
- Give space for patient-doctor communication, assure that they will be given time to supplement information.
- Plan ahead, prepare for emergency and alternative care arrangement<sup>2</sup>.
- Practice self-care, take a respite break if needed, seek help and support when they feel stress or find difficulty in coping with caregiving.

## CONCLUSION

Beyond the willingness of GPs in supporting PWD and caregivers, additional community support to GPs is required to enable them cope well. Ministry of Health can provide simple referral guides and operation guidelines for GPs and clinic staff in working with PWD and their caregivers. Literature on caregiver burnout, self-care, and up-to-date community resource directory can be made available for distribution to caregivers. Simple assessment tools can be developed to aid assessment of caregivers' wellbeing by GPs. Health ministry can also provide platforms for closer liaison between GPs, agencies and other professionals. As some GPs impose additional charges for longer consultation time, subsidies to PWD for such purpose would also be helpful. It is recommended that research be done on the care triad comprising GPs, PWD and caregivers or on related topics to identify salient issues and best practices in Singapore.

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## LEARNING POINTS

- It is important for GPs to cultivate supportive relationship between members of the care triad in order to optimise the healthcare for the PWD.
- Caregiving can be a challenging task and have both positive and negative impacts on caregivers' physical, mental, psychological, social and financial wellbeing.
- Timely support to caregivers can help to reduce stress, burnout and depression, so that they can continue to provide quality care to PWD
- GPs can help to enhance the healthcare experience of PWD and caregivers, with some external support.