

Relief for caregivers

By Yam Phui Yee

What can you do in four hours on a Saturday morning? For single mum Myra*, plenty.

Her four-year-old son, who has autism and attention deficit hyperactive disorder (ADHD), is some place safe where he is preoccupied, enjoying himself.

For a short while, she does not have to worry about him. Her mind free, her worries eased, she can think about enjoying personal time in the salon to cut, perm and dye her hair. Myra visits the hair salon, three times a week. Each time, it is one big rush.



Getting a break ... Chee Pang (left) gets to know his caregiver. Pictures by Daniel Lee

"I have to wait till my son sleeps, rush to the hair salon for over an hour and come home quickly. He is very attached to me. If he sees me leaving the house without him he will throw a tantrum," says Myra, a businesswoman.

Since the birth of his son, Jason*, she has not attended any social outing. It was difficult because sometimes he talks and sings to himself, or does actions that draw stares from people around. But Myra is used to all that now.

Like parents all over the world, she knows that caring for a child with special needs can be a 24/7 job as parents often have to monitor closely and groom, feed and clean the child. Some have to handle feeding tubes, oxygen tanks and syringes daily. Frustrations and fatigue are not uncommon among parents.

For many such parents, relief – even if temporary – is not an available option.

But, now, thanks to the Pemancar House Respite Care Service, parents like Myra can look forward to having a few hours to themselves, whether to pay the bills, do grocery, swim or simply get their hair done in one sitting!

The Pemancar House Respite Care Service is a collaborative pilot project by two NGOs, the Asia Community Service (ACS) and BOLD Association for Children with Special Needs, Penang. Caregivers can leave their wards at Pemancar and take time off to do whatever they want to do.



Khor ... caregivers need to rest.

The service is known as "respite care" and is the first of its kind in Malaysia, says ACS executive director Khor Ai-Na.

"Respite care is short-term relief and a break given to families who are caring for their children with special needs. Caring for a child with special needs can be exhausting. Continuous caring is stressful and unhealthy and all caregivers need to rest.

"Similarly, children with special needs also need a break from their caregivers. It might be a surprise to some people that children with special needs also can have an 'overdose' of treatment or overload on learning and therapy! Giving both parties a temporary relief is vital to renew energy and relationships," said Khor.

Unlike day care, respite care focuses on the well-being of the parents and caregivers instead of babysitting or teaching children. Respite providers take over the responsibility of the caregivers thus, freeing them to have some time to themselves while their wards are being cared for.

In the United States and United Kingdom, respite services are available for caregivers of children, youths, adults and the elderly who are frail in health, disabled or suffering from mental illnesses.

According to the ARCH National Respite Network and Resource Center, US, respite lowers the sense of isolation in families, provides rest and relaxation, maintains family stability during crisis, and helps preserve the family unit by decreasing pressures that might lead to divorce, institutionalization, abuse and neglect.

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Last year, ACS and BOLD carried out a survey among families with disabled children. Of the 89 respondents, 50% had not heard of the term "respite". However, 57% said they were willing to give respite care a try and 17% agreed that they needed it very much.

They were also asked what type of services they would like.

"From the survey, the most requests were for emergency respite (70%); followed by school holiday respite (51%) and social clubs (35%). Looking from the response, it would seem as if parents are still looking for ways to keep their children occupied rather than acknowledging the fact that they need a break," says Khor, who is also BOLD vice president.

The Pemancar Respite Care Centre was started in April this year in Gelugor, Penang and offers half-day respite service at RM20 per child, with subsidy and waiver options available for needy families. It is also seeking funds to run the service, which requires an operating cost of RM2,500 monthly.

Initially, the parents felt guilty about taking time off initially.

"At first, I just waited Jason at home and would be on standby in case of an emergency situation at the respite centre. Now I go shopping or just sleep without feeling guilty anymore," says Myra.

These days, Jason waves a happy goodbye to Myra when she leaves him at Pemancar and spends a fun morning with the drum, sand pit or toys.

There is no doubt there is a great demand for respite care in Malaysia, but a more urgent need is to raise awareness among policymakers and caregivers on the benefits of respite care.

In the US and UK, for example, demands from families giving long-term care to their elderly, sick or disabled family member paved the way to push for new legislations requiring federal budget allocation for respite services.

It makes sense: supporting families to care for an ailing, ill or disabled family member cuts down reliance on professional long-term care and thus saves on healthcare systems and taxpayers' money big time.

A 2006 study by Evercare and National Alliance of Caregiving noted that respite care was one of the most frequently requested service by caregivers in the US.

Although the idea of respite is still relatively new in Malaysia, those who have tried it see the benefit of such a service.

Subcontractor Teoh Eng Hock was devastated when his youngest daughter was hospitalised a few years ago. While his wife stayed in the hospital with their daughter, Teoh had to stay home to look after his son, Chee Pang, and was unable to visit them.

Chee Pang has severe cognitive delays and needs assistance to eat, clean and dress.

"A teacher at ACS helped us to take care of Chee Pang for a week. Only then did I have time to visit my wife and daughter in the hospital," says Teoh, 54.

This was an informal case of emergency respite and it came in the nick of time.

With organised respite at Pemancar House now, Chee Pang drops in once or twice a week so that the rest of the Teohs can recharge their batteries, go for a walk by the beach, hike, shop with ease or catch up with friends.

Teoh feels the tendency of a family break up is very real given the stresses and pressures families with special children go through. It is especially a serious issue for young couples who do not have family members or relatives living nearby to provide short-term relief.

"Respite service is really needed when a parent falls sick. You need a safe place to put your child," he says.

Taking time off does not mean parents care less about their children but rather, the opposite is true; parents need to recuperate and be refreshed for the long-term job of raising their children well.



Chilling out ... Teoh (right), his wife and daughters enjoying family time by the Batu Ferringhi beach while his son Chee Pang spends a few hours at a respite care centre

"Now, I appreciate our time away from each other as we both need a breather as well. It is a time to recharge especially on the weekends, when he would otherwise have been with me for two full days without any break in between," says Myra.

"I have to admit that it is very stressful when you have a child who demands 24-hour attention. And for him, having a mum who demands him to do things her way is equally stressful," she confesses.

Some parents, like Myra, rely on a domestic helper to look after their child with special needs at home. But, maids need a break too.

"We realise that many families have domestic helpers or maids but maids also need a break. If they don't get a break, do you blame them if they release their stress on the child?" asks Khor.

Teoh prefers not to hire a domestic helper to avoid having to train a new maid every three to five years.

Before Pemancar House was established, Teoh and a few families had tried organising an informal respite care service. Each couple was to take turn babysitting a few disabled children while their parents took a break.

However, the plan did not take off as caring for a group of children with various disabilities and childproofing the house turned out to be formidable challenges.

The pilot project in Penang will perhaps set the example of how respite care service can be provided in the local context.

*Names have been changed for confidentiality.

*Pemancar House Respite Care Service

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Teoh ... respite care services are really needed