

# Take a break, care-givers

By LOH SIEW HAR

## Breaks are vital for the well-being of care-givers of children with special needs.

IT'S Saturday morning and Peter goes to Pemancar House in Glugor, Penang, as usual. He takes off his shoes, puts them on the shoe rack and prepares to walk straight into the house. He waves goodbye to his parents when they call out to him: "Pete, bye". Then his parents leave with wide smiles on their faces, going off for a few hours to spend precious family time with their other children.

Peter, a 17-year-old with severe autism, is the second child of Mr and Mrs Lee. Everyday he spends his time roaming around his home as there are no available care-giving services suitable for his age and needs.

His mother, the main caregiver, has not taken a break since his birth. She was able to get her much-needed respite only after Pemancar House began operations in March this year. Pemancar House Respite Care Support Centre is a joint project between Asia Community Service (ACS) and Bold Association for Children with Special Needs Penang (Bold Penang).



Win-win: Respite care provides children with a change of environment and an opportunity to socialise with other children.

"There were times when we desperately needed someone to look after Peter so that we could attend to an emergency situation. But we just couldn't get the help. So either my wife or I will have to stay with him. As my elder daughter grew older, she took up the emergency carer's role. Still, this is a heavy responsibility for a 19-year-old," said Mr Lee.

"Sometimes we really need a break to recharge ourselves and to spend more time with our other children," he added.

Jason also goes to Pemancar House every Saturday morning. When he first started two months ago, he cried when he saw his mother leaving. Now he happily waves goodbye to her.

"I was so worried on the first day. I felt guilty for leaving him so that I could take a break," said Vera, Jason's mother. "But now I feel so relieved to be able to have a nice meal and do a bit of shopping with my visiting mother, knowing that Jason is safe in Pemancar House," said Vera, a single mother.

There are many more parents out there who need a short break from their special needs children, but are not able to find it.

For most of us, going an outing with friends, shopping for groceries, or even attending a wedding, may sound trivial. But to families with special needs children, especially those with severe disabilities, and to single mothers like Vera, these are luxuries that are hard to come by.

Caring for someone can be a full-time job. When the task involves looking after a special needs child, the responsibility can be overwhelming and stressful for the caregiver.

The caregiver needs to take a break sometimes. Some caregivers may feel guilty or apprehensive about taking a break.

However, if the caregiver has been providing care for too long without taking a proper break, she or he may become ill, anxious or depressed. This can make life even more difficult for the caregiver and the person under his or her care. It is no wonder why some children end up in residential institutional care.

What these caregivers need is "respite care" or "short break care". This concept of providing temporary relief to families caring for a child with a disability is fairly new in Malaysia.

Can respite care meet the needs of Malaysian families who have children with disabilities? Are Malaysians ready to take up the role of respite carer? To get some answers, a small survey was conducted last December. Based on the families' responses, ACS and Bold Penang jointly piloted the Pemancar House Respite Care Support Centre.

Recently in August, we were fortunate to learn more about respite care from Luke and Rachel Bulpitt, a couple from Reading, England, who are registered foster carers and approved respite carers for children with special needs.

Luke (who works four days a week as a solicitor) and Rachel got involved in respite care when they were foster parents for a baby boy named Eric who had multiple disabilities from birth.

Eric required special care such as feeding through a tube, frequent mucous and phlegm removal through suction, and had to be frequently carried. The Bulpitt's family life was severely affected by caring for Eric. They were stressed out and hardly had time for their two daughters. They reached out for respite care.

Having experienced the benefits, they decided to take on the role of providing respite to other families after Eric passed away.

In Britain, local councils are legally required to provide some kind of respite care after a survey discovered that this is the most needed service for families of children with disabilities. Respite care can be centre-based like Pemancar House, in a respite carer's home, or in the home of the person with disability. The Bulpitt family runs their respite care mostly in their home but Rachel sometimes provides respite care in the home of a person who is dependent on an oxygen machine.

From their experience as user and caregiver, the Bulpitt family shared with us the importance of having respite care. Respite care provides the parents with a break that helps them to de-stress and to recharge their batteries. As a result, respite care helps to reduce abuse, neglect, and/or abandoning of a child with disability. It also provides the parents with opportunities to have quality time with their other children.

Last but not least, it provides opportunities for children with disabilities to have a change of environment and to have social interaction. This is particularly important for those who are home-bound or come from single parent families.

*All names have been changed to safeguard confidentiality. Asia Community Service and Bold Association for Children with Special Needs Penang are NGOs servicing children and young adults with special needs. To learn more about Pemancar House Respite Care service, call 04-658 7857 /017-478 5193 or e-mail: [respite\\_pg@gmail.com](mailto:respite_pg@gmail.com).*