

## Timely gift of time

By Yam Phui Yee

There was a time when Luke and Rachael Bulpitt had to carry a huge bag of medical equipment every time they went shopping. Freddie, the cerebral palsy baby they were fostering, needed to be fed from a tube inserted through his nose.



Carers of carers ... Rachael and Luke came to Penang recently to train local staff in giving respite care. Picture by Yam Phui Yee

Doctors said Freddie had very slim chances of survival and gave him a certificate to celebrate his 100th day of birth. Freddie could not sleep well at night and wanted to be held all his waking hours.

“We felt so exhausted. We also realised we couldn’t spend time with our children,” said Luke, father of two daughters, aged 10 and 13.

Luke is a lawyer who works four days a week. His feelings are common among caregivers who give constant, long-term care to a family member with special needs or who has mental illness or is frail in health.

In-home care is cheaper than institutional placements, keeps the family together and fosters a better understanding of the person with needs or illness.

Luke is one of about six million adults in the United Kingdom who are providing care for the disabled, sick or elderly relatives and friends.

A recent survey in the United States estimated that 65 million American family caregivers or 29% of the population provide about 80% of long-term care.

Caregivers are known to suffer from stress, fatigue, ulcers, high blood pressure, depression, feelings of resentment, anxiety, guilt and loneliness. Taking regular short breaks gives them a much needed rest and an opportunity to chill out with friends, catch up on movies or simply recharge with a massage.

Respite care provides the much-needed short breaks to the disabled, ill or elderly and their caregivers. It can take place at their homes, at the home of the respite carer or a dedicated centre.

Unlike daycare or a learning centre, respite (the word can be used interchangeably with “respite care”) , sometimes referred to as a “gift of time”, supports families by giving caregivers a break and letting the child meet new people to develop emotionally and socially.

Respite care provides the much-needed short breaks to the disabled, ill or elderly and their caregivers. It can take place at their homes, at the home of the respite carer or a dedicated centre.

Unlike daycare or a learning centre, respite (the word can be used interchangeably with “respite care”) , sometimes referred to as a “gift of time”, supports families by giving caregivers a break and letting the child meet new people to develop emotionally and socially.

Luke and Rachael are registered foster carers and respite carers for children with special needs in Reading, UK. In the last five years they have been providing respite care service at different times to 13 children mostly with autism spectrum disorders. Children placed in the care of respite givers are known as “link children”.

Luke works four days a week while Rachael is a full-time carer, which gives her time to visit some of her link children in their homes. The Bulpitts now have four children coming over to their home over 10 to 12 days a month.

“What we do depends on the child. We have a (link) child with autism who enjoys football and swimming; a boy who likes camping and going to the beach; and a girl with Asperger’s syndrome who likes to just sit and watch, play games, look at books – she doesn’t do much,” said Rachael.

She is used to sharing her home, bed and even parents with other children. Rachael has four sisters and grew up with about 10 other girls her parents fostered. Each spent different lengths of time with her family.

She went into fostering and respite care because she wanted to do the same thing her parents did for others.

The Reading local authority pays her a small weekly fee of £200 pounds (RM996) to keep her available for the job. It is a job, Rachael admitted, but watching the children enjoy their break keeps her going.

“You feel you are doing something positive for them, you can see it. Sometimes you feel you want to stop but you can’t, you have a bond with them. If you stop, you won’t see them again,” she said.

Respite care has shown to delay or prevent expensive out-of-home placements and therefore keeps the family together; strengthens families by reducing stress and divorce; decreases the risk of abuse or neglect; and cuts down on hospitalisation and medication.



The Pemancar House Respite Care pilot project in Gelugor, Penang.

It also saves the country lots of money. A 2007 study by American advocacy group AARP estimated that informal caregivers – family members, friends and spouses – saved the US economy US\$375 billion (RM1.16 trillion) because they did not have to put their wards in institutions.

To maintain this saving, it becomes apparent that informal caregivers need to be supported with respite care.

American businesses lose US\$17.1 to US\$33.6 billion (RM52.7 to RM103.6 billion) annually in productivity costs due to stress, workday interruption, absenteeism and resignation caused by informal caregivers, reported another study by the National Alliance for Caregiving and the MetLife Institute. With respite care, that cost would be reduced.

Respite care is relatively unheard of in Malaysia, except among social workers and policymakers.

In developed countries like the United States and UK, demands for respite care from families and non-government organizations have resulted in significant achievements in pushing for legislation and funding for big-scale respite programmes, although funding remains a major challenge in current economic conditions.

In Malaysia, the closest piece of government policy that supports respite is perhaps the National Senior Citizens Action Plan. One of the activities listed under the plan is to encourage NGOs and volunteer organisations to provide respite care for caregivers of bedridden senior citizens at home.

Welfare department (JKM) director-general Dato’ Meme Zainal Rashid said respite care is one of the support services identified to help caregivers of the elderly, ill and children get rest and short-term relief.

“At present, JKM has yet to provide this service but it is in our plan. It will be implemented using a smart partnership approach by indentifying suitable NGOs to provide the service with funding from JKM,” he said in an email interview.

The department did not have information on any respite care providers in the country although Meme believed there are NGOs which offer it informally. No timeline was given as to when and how the department planned to implement the smart partnership.

A source said a lot of system structures needed to be in place before respite can be nationalised.

But Malaysia needs to start somewhere.

In Penang, the NGOs Asia Community Service and BOLD Association for Children with Special Needs have started what could be the first respite care service for children and youths with special needs in April this year.

Although the service was publicised among over 300 families, only a handful took advantage of the pilot project. Those who have tried it enjoyed the breaks immensely.

Luke, who was in Penang to train staff and volunteers for the respite project, said parents often feel guilty for leaving their disabled child with someone else. They would sit at home worrying about their child until they realize that both they and the child actually enjoy the time out!

You know respite is greatly needed when caregivers give feedback like “just to be able to take a bath uninterrupted” and “able to do all the things we can’t do when the child was with us”.

“It makes you respect the caregivers who take care of them all the time,” said Luke.

Rachael agreed. “I don’t know how they do it and how they manage. They can’t stop. You know how much they need and appreciate it even though they don’t say so.”

Baby Freddie passed away after staying for five months with the Bulpitts. While Luke and Rachael play with their link children when their parents go for a date or go hiking with the rest of the family, they support the child, family and country even though it is just forking out a few hours to give others a well-deserved break.

### Share this article

FACEBOOK [f Share](#)

TWITTER [Tweet](#)

EMAIL THIS [Email](#)

SHARE [ShareThis](#)

### Related Article:

[Relief for Caregivers](#)