

MC 21/5/08

## Caring for Carers

I am sitting at my computer wondering where to start talking about the needs of carers...

I am a parent of three grown up children, one severely disabled. My 25 year old son is a young man who is visually impaired, spastic quadriplegic with epilepsy and no speech.

Yet compared to the great numbers of ageing parents of disabled young adults that I have come into contact with over the years, I consider myself blessed...

I have two independent, healthy, intelligent and caring children. My disabled child is a wonderful young man who, in spite of his massive disabilities, manages to maintain a cheerful, loving disposition. I also still have a loving, caring husband, which means that I am one of the few parents of a disabled child whose marriage or partnership hasn't broken up. I have been told that 70-80% of relationships where there is a disabled child do not survive...

So why am I writing about the difficulties of caring for a disabled child? Because in spite of the blessings, after years of juggling my life so that it could be lived as normally as possible, I am finally exhausted...

My other two children have left home to pursue careers and life, as I had always hoped they would. Their help in caring for their brother is no longer there.

My husband is working as hard as ever contributing to a retirement plan for the three of us and I am wondering how I can face going back to work after taking time off for an overdue operation.

I am 58, with a University degree, but due to my caring responsibilities, with difficulty, I have only ever managed a part-time job.

What happens to a family that cares for a disabled person? In our case much joy at seeing unconditional love from the disabled child and giving back to him in return. Joy at seeing how everyone in the family rises to the challenges offered on a daily basis.

However, along with these positives come the negatives. The sleepless nights, the endless visits to GP's and specialists. The expensive equipment needed to give the child any quality of life.

The strain on the primary carer's relationship with her partner. The inability to meet all the family's needs. The family's grief at the sight of the enormous and often unsurmountable challenges faced by the disabled child.

As the child grows into adulthood, there are then the innumerable struggles with Government bodies that inform you that there are no funds for respite, for day programs for the disabled young adult once they have left school, no funds for equipment.

Respite, both in home and particularly out of home when the disabled child is older, allows the carer to recharge emotionally and the young person to spend time with other young people, both disabled and carers.

Then there is the greatest challenge of all. How to look after our children after we are gone...