

Better Support for Carers

I am emailing to you at the request of Judy I . i am unsure what exactly i have to say in this email but i will do my best to make it concise.

My husband, Victor and myself have two young daughters, Tania 31 years old and Nadia who is 28 years old.

Both of my daughters had a stroke when they were 8 months old.

My eldest daughter, Tania has an intellectual disability from that stroke and also suffers with grand mal epilepsy and is also on medication for thyroid dysfunction.

Tania is classed as a 'high functioning' young woman with 'special needs', in particular, her need for ongoing, daily supervision for day to day routines and also for her vulnerability in an unsupervised environment.

My husband and I have cared for both our daughters and do not under any circumstances wish to push either of them out of the family home, however, we are both in our early sixties and would like to see both of them settled and in care that is appropriate for their needs.

Most of my advocacy regarding supported accommodation has been for Tania, as Nadia would be able to live independently with limited support at this point in time. However, Tania would need 24 hour support.

I have tried to place her name on a case management 'waiting list' without success for various reasons.

I believe that the best approach would be a 'transitional' move from the family home to other care, so the impact to her and us is the least disruptive as possible.

This issue of supported accommodation has been left neglected for a long time. I would like to see firstly, an appropriately, monitored 'intake' process for referrals so that the 'body' who is in charge of the 'intake and referral/placement' system has a clear indication of the needs in different areas.

I do not feel confident that any one organisation has that 'intake/referral/placement' system at a satisfactory level at this time.

Carers/parents need to know that when the time comes there is going to be somewhere who will be able to take care of their young adult and that they are not placed in the first available placement somewhere miles away from where they have lived and not known to anyone.

It is FEAR that drives me with my ongoing advocacy

Thank you for your consideration and i do hope the above information is helpful to your intervention for us.

Best regards

Rhonda

Rhonda
AOD/MRRC