

MC 21/8/08

What Carers Need

About us:

- * My eldest daughter, 21, has a severe intellectual disability and functions at the level of a two year old.
- * Secondary student children and parents in early 50s
- * Main income earner is a teacher
- * Secondary income is from casual IT work. I cannot get the requisite flexibility in permanent positions. Hence I have no paid leave for daughter's illnesses, family holidays etc.
- * We live in southern Sydney.

We are an intact family and expect to continue to provide care for her at home for at least the next decade. (Just as well, we have no conscionable choice).

About our daughter:

- * She is physically mobile but will leave any unlocked/unsupervised premises and walk until she is trapped (ie locked in a strangers car or house, on a main road etc)
- * She is shy and passive so an easy target for the unscrupulous.
- * She cannot construct intelligible sentences nor answer questions.
- * She can feed herself (ie she can put prepared food in her mouth, chew and swallow) but at the end of most meals she will need a change of clothes.
- * She can wash her hands but not the rest of her body. Her personal hygiene when menstruating is non existent.
- * She can undress herself fully, and frequently does regardless of the context.
- * She suffers from multiple epilepsies leading to daily seizures
- * She has frequent minor illnesses largely stemming from her lack of hygienic practices

Current Services:

She attends a post school options day programme from 9-3 (with transport 8.30 to 3.30). We receive about 30 days respite per annum - generally in 3 day blocks.

What we want:

* A path to supported accommodation for the long term.
Our younger children should not be expected to structure their adult lives and relationships around their sister's needs (as everyone does now).
We need to know there are options for a safe long term home for her so we can plan our retirement and her care after our death.
We need to see her settled and cared for before this becomes an emergency situation.

- * Flexible respite that allows us to take longer breaks as a family

Regards
Jenny