

C15

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Solva Care
Response from Solva Care

Report from [REDACTED]

[REDACTED] Web site www.solvacare.co.uk

I spoke with two people from the village who have cared for many years for relatives suffering for dementia.

MS cared for by son , S.

Suffered early onset dementia. Looked after by son (S) for 7 years (from 2010 to 2017). He has had experience as an ancillary health worker. MS had confused memory loss (Conflation of memories from different times). In the early stages she was physically fit and loved walking and singing. At this period she walked and sang with Solva Care volunteers whom she knew and trusted.

MC. cared for by wife, E.

Suffered dementia from 2006. Then complicated by strokes leading to mental confusion and loss of vision finally leading to blindness. Cared for by his wife (E. 70 – 80s). Daughter supportive but did not live near. MC was a proficient singer, reciter and dancer. He continued to enjoy singing and dancing even after the first stroke and did so at Solva Care's Friday Club until he became too confused to do so.

From what they told me the following problems emerged.

Problems

Lack of sign-posting

E was not given links to useful organisation or advocates until very late in MCs illness. She was not referred to any useful agency or advocacy till 2015 when the psychiatrist suggested a memory café. By chance at this venue M & E met an advocate who proved very supportive.

S. felt entirely on his own with nowhere official to turn

What would help. Medical practitioners should routinely give links to useful organisations as early as possible, even before actually needed. Carer will then know where to turn when crisis points arise.

Lack of practical support.

E. got no support to know how to cope with M's multiple difficulties (visual problems, losing recognition of everyday items such as knife, fork, spoon, night-time wanderings. Written information was far too lengthy and complicated for E to read when under stress and tired. A Carers Assessment form was partially completed but not sent in. "Too complicated. All I needed when he came out of hospital was information on how to cope with a blind person, some pop-in visits and some respite visits."

"Where the client is part of a couple, it is assumed that the other one will be able to cope".

What would help. *Written information and guidance should be given in simple language. Perhaps official forms for assessment etc should have a simple part 1 where applicant explains situation and what support they feel would be helpful. Part 2 could then be completed if necessary (with assistance) to apply for allowances, respite care, residential care etc***Lack of co-ordination between agencies and departments**

On requests for help, agencies were very slow to act and action was usually adding M to a waiting list. Many different people were phoning E which was confusing for her and even for her daughter. Even different departments in the hospital seemed unable to coordinate. Eg. Doctor said appointment should be in 2 weeks, when letter came it said 6 weeks.

S. was told that MS could no longer be part of the group as she was “disruptive”.

What would help. *Re-instate the designated social worker (or other designated person) so that the clients situation is understood at least by 1 person outside the immediate family. This could also help with dementia sufferers who might be able to set up a relationship with designated person they know and trust.*

Confusing (or lack of medical) information.

After laser treatment on eyes E was told “Give the eye drops “till they run out”. Another practitioner said “Eye-drops are for life”. Staff at the laser surgery clinic were unprepared to answer questions on eye-drops because “they only did laser surgery”.

Doctor said MC should not be discharged without a care package. He was discharged without any package or information.

GP prescribed unsuitable drugs that (on investigation by carer) were contraindicated for the condition

“Admission by the authorities that they did not know how to treat the condition and talking therapy would have been more useful me (carer).

What would help. *Written information and guidance routinely given in simple language with contact information and signature. More opportunity for carers to talk with experienced people about their and their dependent’s situation.*

Need for advocacy to cope with the system.

Advocacy service was not sign-posted at all. Advocate (Alzheimer’s) was encountered by chance at a memory café. MC’s daughter had to fight for suitable appointments and for thorough check-ups. Mother several times said “What would we do without you.” Daughter’s comment was “Without me Mum would probably be dead.”

What would help. *Existence of the Advocacy services should be sign-posted by medical practitioners as early as possible. Carers will then have someone to turn to when critical situations arise.*

Poor administration.

Financially E had to pay for everything. She thought that both their savings had to be taken into account when it should have been only MCs. She found this out too late.

Pemb's Social Services Finance department seemed incapable of providing appropriate timely bills.

What would help. . The system for assessing financial aspects is inadequate putting immense burdens on families. It should be simplified and more support given to families earlier to understand their entitlements.