Cyflwynwyd yr ymateb i ymgynghoriad y <u>Pwyllgor Iechyd a Gofal Cymdeithasol</u> ar <u>Cefnogi</u> pobl sydd â chyflyrau cronig

This response was submitted to the <u>Health and Social Care Committee</u> consultation on <u>supporting people with chronic conditions</u>.

CC79: Ymateb gan: | Response from: Katrina Owen

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For your Attention

I would like to share a personal story that I feel highlights concerns regarding lack of social support for seniors in Ynys Mon who fall under the care of Betsi Cadwaladr. Given that the Health Board is currently under special measures I am sure you have received multiple concerns but I hope you do take note of my story, as with everyone else's concerns the human impact is significant.

My parents

My Father and Mother are seniors and have been married for over 50 years. Dad is a RAF Veteran and Mum was a homemaker. They have 4 children, 3 of whom, including myself, live outside of the UK. They live in a small terraced home in ______. They have neglected themselves, largely due to alcohol abuse, stubbornness and pride. My mother is an alcoholic and has not had a mental health assessment but spends her day drinking, incontinent, and yelling abuse at my father. At night she screams things like "he is killing me" at the top of her voice all night long. She may be having hallucinations but no one has assessed her. I feel she would be a strong candidate for a diagnosis of bipolar disorder or alcohol related dementia, or even Lewy Body Dementia, but as she has not had a mental health assessment or a referral to a geriatrician we will never know.

My father tolerates this verbal abuse very reluctantly, because, as he says, he made a vow when he married her and she is ill. He endures verbal name-calling, screaming and physical abuse every day and most of the night. He stays awake as often as he can to try and calm her because he is embarrassed his neighbours will hear. He also has medical issues, AFib, Hypertension, peripheral arterial disease, borderline diabetes, untreated depression, cognitive decline and alcohol misuse.

Family reach out for support.

Pre-2021: My sister lives in the same town and has unfortunately had the bulk of the responsibility to look after my parents put on her shoulders. My sister herself has a chronic illness resulting in days when she is physically unable to help my parents. She has been reaching out for support at the local family practice but as there has been minimal physician attendance, it has been extremely challenging. I had travelled from Canada to support her and take my mother to a physician appointment in the hope of the physician being skilled enough to persuade my mother to accept referrals to mental health. He did nothing, ignored my presence in the room, asked how she was, she said fine and he gave her some AA leaflets which she promptly threw in the bin. I flew back to Canada with no plan of care in place.

2021: My mother at this point was housebound, refusing to wash, incontinent, and abusive to my father. After multiple reach outs for support, including to the Betsi Cadwaladr Patient Safety and Experience, we finally were given the name of a physician who would support us. We were asking for someone who would assess both of my parents and determine their immediate needs, including the need for home support, nursing visits for chronic disease management, mental health support, and capacity assessments. I spoke at length to this physician and expected a plan of care to be set up. We were promised this would be done but no home visit was made, instead my father was seen at the Family Practice but my mother was not seen. My mother developed a pressure sore and at that point, we were able to get a nurse to visit. The house was in disarray and odorous, and my mother had been incontinent everywhere and I mean everywhere, the nurse did the bare minimum and my mother told her not to bother coming back. Social Services phoned, my mother answered and told them "No" so they never came.

2022: I came home in the hopes of meeting with a physician - the one I had spoken to previously was now no longer available and I couldn't convince a physician to come to the home. I spoke to Social Services, and while I was standing next to my parents, they refused to listen to me and insisted on speaking to one of my parents, I put my father on the phone, and he proceeded to tell them that he does need help but not now as his daughter was visiting, so they refused outright to come and crossed them off their list. In fact, they accused me of threatening behaviour because I was begging them to listen to my concerns, they told me my concerns didn't matter, my father had told them they weren't needed so they wouldn't come.

One day my dad walked out of the house in the early hours of the morning and couldn't be found. We called the police and during the investigation, and in my understanding of "Duty to Report" I told the police about my mother's abusive and coercive behaviour. Their instant solution was prosecution of this frail, housebound, mentally ill woman. Of course, my father, when he was found, refused to prosecute so the police told me the best they could do was put them on a list of vulnerable people and they would be talked about every week at the local hospital on the Safeguarding committee. Still no one came to assess them. We have no idea who talked about them and what was said, who the Lead Practitioner was and what planning and intervention has been put in place.

In October 2022 my father, completely exhausted after spending months sleeping in a chair because he wanted to limit my mother's screams, ended up in hospital for a week with severe cellulitis. I begged the ward staff not to send my father home without social work involvement, that the situation at home was dire and my father needed help. Again I wrote to Betsi Cadwaladr Patient Experience. My father went home to the same situation.

2023: In April we finally had a social worker to help. She has been supportive but her ability to put in practical support have been hampered by the sheer lack of support available. A GP finally did a home visit, was kind and compassionate, ordered blood work, and then told my parents to stop drinking, it was not enough. Social services still refused to come because my dad had "declined services", the social worker intervened and they were put on a waitlist for a "Care Package". However, we still waited for a mental health assessment for my mother, my father was still enduring daily abuse and even though I believe he is a victim of abuse and is an "Adult at Risk" under part 7 of the Social Services and Well Being Act, 2014, nothing was being done to support him because he refuses to prosecute a frail, elderly, mentally ill spouse.

Current state: My father was readmitted to hospital with blood clots in his legs and in his heart. He was so confused and exhausted that he had forgotten to take any of his prescribed medication, including an anti-coagulant, for months. It's difficult to check on these things when I live in another country and he tells me he is fine. However, there were no red flags raised from the family health team who should have been monitoring his medication on a regular basis. Dad had an above-knee amputation, at 80 years of age, because, in the previous three years, there had been zero support for a man who was clearly struggling despite the fact I had reached out for help on multiple occasions. Think of the health system costs now endured because my father didn't get the support when we asked for it.

Now he will not be able to return home- it will not be able to be adapted for his living. He is now hospitalized until a retirement/assisted living facility can be found for him.

My mother is now living at home alone. Still yelling abuse to her daughter who calls in to deliver food, that she won't eat. She refuses to wash, remains incontinent but now, at long last has a daily carer to check in on her. However, as expected Mum has demonstrated behaviours of concern, and although she has agreed to be placed in a retirement home, not a single home will accept her because of her behaviours. However, the hospital for Elderly Mentally Infirm will not take her because she will "willingly go to a home" and therefore cannot be sectioned.

Solutions

- 1. Community support needs to be holistic and include a family centred approach. Never has my dad said he doesn't want myself or my sister involved in the care planning for our parents, however the health system completely disregards us, even with a LPA, because my parents are considered to have capacity.
- 2. Family Practices should be fully functioning, even more so one may argue, in an area of poor social determinants of health. It is not ok for a community to be constantly told they have no physicians.
- 3. Family physicians should see home visiting as an integral part of their assessments, a good deal of information can be gathered by seeing someone in their home environment.
- 4. Family practices should have Chronic Disease Management Nurses who focus on the vulnerable population, provide preventive care, health education, health assessments, navigate social supports and complete home visits. Such a nurse can build trust with the person in need and therefore will have more possibility of ensuring the right supports are in place for successful independent living or help them make choices.
- 5. Physicians need further training on Mental Health and Social Determinants of Health, it is not ok to tell seniors who have been drinking all their lives just to stop drinking, they need a much more developed plan of care. Nor is it ok to assume that because someone "declines support in the home" they don't need it, people who self-neglect don't want to show their neglected homes but if they develop a trusting relationship with the home support agency mountains can be moved.

- 6. Acute care facilities shouldn't be just task focused curing my father's cellulitis with IV antibiotics did not solve his long-term problem of sitting up in a chair all night being afraid to sleep in case my mother's screams upset the neighbours. The inability for my father to raise his legs and sleep significantly contributed to his infection and poor peripheral circulation. The facility should have ensured there was a deliberate follow up plan when my father went home. Discharge planning for complex cases should involve a collaborative approach with all key partners, family, chronic disease family practice nurse, district nurse, social worker, home support supervisors and most responsible physician.
- 7. The "Duty to Report" for adults at risk should involve a comprehensive solution. In our circumstance I do not believe that adequate Safeguarding Procedures have been put in place, given that my father chose not to prosecute. Early intervention has been key and has not been possible due to lack of support. The Safeguarding Procedures should not just be a written document that talks about person-centred holistic care. Any interventions planned need to be acted on, and the family involved need to know what those plans are.

I appreciate your interest in the concerns I have raised here and very much look forward to the possibility of seeing solutions for the seniors in North Wales in the near future.

With kind regards,

Katrina Owen