

ASI Submission on the Future of Mental Health Care January 2018

In this Submission ASI presents its views on the challenges and needs of people with dementia in relation to mental health care, particularly regarding services, supports and perceptions of dementia and psychiatric illness. This Submission represents the views and responses of ASI staff, including Operations Managers and front-line staff.

Dementia and Psychiatric illness

Dementia is a neurodegenerative brain disorder rather than a psychiatric condition, although the person with dementia may also have existing mental health condition(s), or mental health symptoms related to dementia. People with dementia may develop behavioural and psychological symptoms (BPSD) which cause problems in themselves, which complicate care and can occur at any stage of the condition. These include agitation, repetitive questioning, depression, wander walking and psychosis. BPSD are distressing and problematic for carers as well as the person with dementia; they make a large and independent contribution to caregiver strain and can be a common precipitating factor for institutionalisation. Mental health services and psychiatry of later life traditionally and currently play an important role in dementia care in relation to diagnosis and community mental health supports e.g., via a community mental health nurse, outreach teams of Psychiatry of Later Life, and specialist referrals for people with dementia to neurologists.

Acute involuntary admission of people with dementia to an approved centre for the treatment of mental disorder is only appropriate if the individual case presents with an appropriate mental disorder as defined by the Mental Health Act. Clinically, this is indicated if the individual presents with acute behavioural or psychiatric symptoms associated with dementia, requiring admission. This can result as dementia progresses resulting in transient behaviours and symptoms that require intensive clinical input and stabilisation. Following appropriate treatment, discharge is usually indicated.

Nonetheless, ASI is aware of cases whereby people with dementia have been inappropriately referred to and placed in psychiatric care. In the following case, 85-year old Anne Casey (name is changed), diagnosed with Alzheimer's and living in a residential care home, started experiencing difficulties communicating as her condition progressed and also found it increasingly difficult to understand instructions. She experienced loss of appetite, weight loss and required supervision when taking her medication. Anne's family were informed that their mother was "agitated" and her medication was changed. The family were also informed of an incident whereby their mother allegedly struck another resident although the family felt it was not clear that their mother did strike the other resident and staff could not confirm the incident either.



Subsequently, the nurse manager made a decision to send Anne to a hospital psychiatric unit for assessment. In the hospital the registrar was unclear about why Anne was admitted and believed it was unnecessary. Nonetheless a psychiatric assessment was carried out, and it was observed that no psychiatric intervention was required and no new medications were administered. The team from Psychiatry of Later Life recommended that the acute psychiatric unit was not suitable for Anne. However, the previous residential home now refused to accept Anne, and furthermore any private nursing home that Anne's family contacted with a view to securing a bed for their mother also refused to accept Anne, once they viewed her file from the nursing home. To the distress and frustration of Anne's family, their mother is currently residing in the psychiatric unit, *"Surely our 85-year-old mother deserves the dignity of having a suitable home for the remainder of her life?"*

In Anne's case admission to a psychiatric unit was wholly inappropriate and unnecessary and it is of grave concern that upon discharge re-admission to the residential care home was denied and subsequent nursing homes have also refused the family's mother.

National Framework

There is clear need for the development of a national framework for the provision of consistent systemic diagnosis, appropriate referrals and care responses. This should include management and support of responsive behaviours and BPSD for people with dementia. This framework should involve training of GPs, Primary Care Practitioners (PCPs) and residential care staff to, for example, ensure recognition and understanding of responsive behaviours and provision of appropriate social care responses and carer supports.

Family carers need to be viewed and included as partners in the care of the person with dementia, working with formal care providers. Family carers also need to be supported in understanding and responding to behavioural and psychological symptoms of dementia. This includes learning practical approaches and the increased availability of formal services to provide support.

There is a need for guidance in relation to the reduction of use of psychotropic medications for people with dementia who have responsive behaviours/BPSD (Walsh et al., 2017; Barnes T., 2012, Banerjee S., 2009). ASI is aware of numerous cases whereby carers are deeply concerned about the use of antipsychotic drugs in the management of behavioural and psychological symptoms in family members with dementia, and believe the decision to use antipsychotic drugs needs to be considered with extreme caution.

Integrated Care Pathway Approach

Clear referral pathways are required for people with dementia, and an integrated dementia care pathway approach is required to enable service providers and supports for people with dementia to work in a collaborative and coordinated way, as set out in the National Dementia Strategy. ASI recommends, as an efficient and effective measure, a case management approach to dementia care

integration and co-ordination (Trépel, 2015). Collaboration and coordination of care is crucial for people with dementia, and this should involve all stakeholders in Multi-disciplinary Team (MDT) meetings including ASI services managers if ASI is involved in provision of care. If community based GP/Primary Care is to be the focus of the initial mental health response it would be important to set up a system to train, recruit and fund specialist dementia practice nurses, who could be the link for people with dementia and their families within the Primary Care structure. The latter would be members of the Multi-disciplinary Team (MDT).

In addition, there should be an annual meeting with the primary care team and the service manager of the centre where the person with dementia resides to discuss each case individually. This currently takes place in the ASI day care centre in Kilkenny, and is also attended by the ASI home care coordinator and the day centre manager. This practice can play an important role in understanding and meeting the needs of the person with dementia who may experience responsive behaviours/BPSD.

ASI believes that each resident should have access to healthcare services including primary care, secondary care, specialist services, allied health professionals, and assistive devices to meet his/her assessed needs, irrespective of geographical location or place of residence. To ensure coordination, a record should be maintained of all referrals and prescribed interventions by various service providers for each person with dementia.

Training & Education

People with dementia have the right to health and social care services provided by professionals and staff who have had appropriate training on dementia and human rights to ensure the highest quality of service. Dementia-specific training is needed across health and social care disciplines and in all care settings. Specifically, this should relate to well-informed and trained GPs, primary care teams and healthcare professionals (ASI PBS, 2018). PCPs should promote dementia specific services to patients with dementia, including ASI Dementia Advisors, ASI National Helpline and Information Services, ASI Cognitive Stimulation Therapy, Support Groups and Memory Clinics etc. Training should also include dementia education for residential care workforce.

Adequate support of carers is crucial in supporting the person with dementia, as highlighted in the De-Stress study (Brennan et al., 2017), which was part-funded by ASI. Training is required to ensure understanding of carer stress and assessment of carers' needs assessment, which will be forthcoming in the Single Assessment Tool.

Funding & Resourcing

In order to deliver high standard of dementia care services, appropriate levels of funding is necessary to ensure recruitment of qualified and experienced staff. Within the above framework, there is a need for funding to ensure the introduction of dementia specialist nurse practitioners. It is

also proposed that the HSE should fund an ASI safeguarding officer, as addressing safeguarding issues for people with dementia can be very time consuming and lengthy.

Furthermore, funding is required to ensure that service buildings are equipped with modern equipment while maintaining the building to acceptable compliant standards in relation to health and safety. Also important is funding for external therapeutic interventions and for provision of appropriate and meaningful therapeutic activity equipment for people with dementia. This is vital to support people with dementia to develop self-help skills and potentially developing other life skills and can also help alleviate responsive behaviour resulting from agitation and distress.

Beyond a Medical Model

Policy and practice should aim to support people with dementia to remain living in their own homes and to maintain existing roles and relationships for as long as is possible. People with dementia should be involved in decisions that affect their lives including the care they receive. This also relates to decisions about acute behavioural or psychiatric symptoms associated with dementia, requiring admission to a psychiatric unit. People with dementia have the right to be provided with accessible information and necessary supports to enable them to exercise their right to participate in decisions and policies which affect them (Charter of Rights for Persons with Dementia, 2016). While there is a tendency towards the medical paradigm, good practice for dementia care should centre on a social and community model that emphasises personhood, strengths and abilities of the person with dementia, and promotion of health and wellbeing.

Bibliography

Alzheimer Society of Ireland, A Charter of Rights for People with Dementia <https://www.alzheimer.ie/getattachment/About-Us/Policy/Human-Rights/A-Charter-of-Rights-for-People-with-Dementia/Charter-of-Rights-for-People-with-Dementia.pdf.aspx>

Alzheimer Society of Ireland, Pre-Budget Submission 2018 <https://www.alzheimer.ie/Get-Involved/Campaigning/Current-Advocacy-Campaigns/Pre-Budget-Submission-2018.aspx>

Banerjee, S. (2009) The use of antipsychotic medication for people with dementia: Time for action <https://www.rcpsych.ac.uk/pdf/Antipsychotic%20Bannerjee%20Report.pdf>

Barnes T.R, (2012) Antipsychotics in dementia: prevalence and quality of antipsychotic drug prescribing in UK mental health services. *British Journal of Psychiatry*, Sep;201(3):221-6.

Brennan, S. Lawlor, B. Pertl, M. O'Sullivan, M. Begley, E. O'Connell, C. De-Stress: A Study to assess the health and wellbeing of spousal carers of people with dementia in Ireland. Trinity College Dublin/Alzheimer Society of Ireland.

The Irish National Dementia Strategy (2014) The Department of Health, Dublin.

Trépel, D. (2015) An Economic Analysis of Home Care Services for People with Dementia. Report independently prepared for Alzheimer Society of Ireland.

Walsh, K., Dennehy, R., Sinnott, C., Browne, J., Byrne, J., McSharry, J., Coughlan, E., Timmons, S., (2017), Residents With Dementia: A Systematic Review and Synthesis of Qualitative Evidence Influences on Decision-Making Regarding Antipsychotic Prescribing in Nursing Home. *Journal of Post-Acute and Long-Term Care Medicine.*