Providing practical care for people with dementia

There are more than 40,000 dementia sufferers in Ireland, with 11 new cases diagnosed on a daily basis, writes **Joanne Flood**

THE increased longevity of the world's population or the greying of society should be celebrated as one of the greatest success stories of modern times. However, old age itself carries increased potential for many age-related chronic illnesses of which dementia one of the most feared.

Dementia in the Irish context

There are more than 40,000 dementia sufferers in Ireland, and with 11 new cases diagnosed on a daily basis, it is estimated that there will be 71,000 active cases by 2026.[1] It is also estimated that 76% of the care of people with dementia (PWD) is by family members in the community or primary care. There are 50,000 family members looking after a loved one with dementia. When residential or nursing home care is examined, statistics have differed dramatically over the years. In 2007, the number of those in long-term care calculated to have dementia was 60-70%.[2] This is a significant figure, although a more recent small study carried out by TCD researchers[3] following mini mental (Folstein) testing in four nursing homes in south county Dublin found significant cognitive impairment in 89% of all residents assessed.

Primary care

From a primary care perspective, at the first national memory clinics conference in 2011, held in the Guinness Store House in Dublin, one memory clinic showed some very interesting findings in relation to individuals who were referred to the clinic for dementia.[4] Of the 58 PWD who were seen over an 18-month period: five had depression, five had low B12/folate levels, and two were suffering from anxiety. This alone shows the importance of fully assessing anyone who may complain of memory problems as, in line with a delirium, there can be many causes of memory loss and confusion particularly in older people.

According to Prof Banarjee, the consultant psychiatrist who led the UK dementia management strategy, only one-third of PWD get a formal diagnosis, and when it happens it is often late into the illness – too late to enable choice, at a time of crisis, and too late to prevent harm and further crises. Prof Banarjee states that the cost of dementia in the UK is more than diabetes, cancer and heart disease put together. To date, the cost of dementia is not as fully researched in Ireland, but in 2006 it was estimated at €400 million with less than 10% attributed to community care.[5]

Testing domains

When someone presents with memory loss, confusion or a change in behaviour or mood it is wise to assess for mood disorder, rule out delirium and to conduct a dementia work up. Collateral history from a next of kin is vital, and if there is no next of kin, engaging with any others who have had access to the patient will be needed. The onset of the presenting complaint will help differentiate a delirium from dementia – although it may be the case that a delirium can superimpose a dementia. This is particularly significant in the acute hospital setting.

Delirium screening should look at ruling out any infective or medical cause of confusion and/or agitation. A full blood work up is needed with a particular focus on an infective screen, thyroid function, and if the patients is on any SSRIs, low sodium levels. Simple but very common causes of delirium in the elderly can be constipation, urinary tract infections and pain.

General testing

General testing domains in dementia are cognition, function, behaviour, and carer strain. Cognitive function includes performing a mini mental exam on the person, being mindful of their level of education with regards to the spelling of world and serial sevens. Usually, any score under 24 needs further investigation to uncover the underlying cause. The Geriatric Depression Scale should always be used with the mini mental exam because depression in the elderly can masquerade as dementia, causing them to score low on the mini mental exam.

Functional assessment can be carried out using different tools to assess their ADL independent abilities. Meanwhile, behavioural assessment can be very tricky: If a family member or relative has brought the person to your attention for behavioural issues, the illness may have progressed and a crisis, such as an aggressive or paranoid event, may have occurred. Behavioural and psychological symptoms of dementia (BPSD) are discussed below.

Carer strain is a very important element in the primary care of someone with dementia. The carer's support, knowledge and coping mechanisms for managing someone with dementia will dictate when the PWD enters long-term care. Working with family members and carers and arming them with the relevant skills and knowledge is required from very early on in the process.

Behavioural and psychological symptoms of dementia (BPSD)

In 1995, the International Psychogeriatric Association (IPA) organised an international consensus conference on dementia and the associated behavioural issues.[6] BPSD are categorised into two domains: behavioural and psychological. Behavioural symptoms include restlessness, physical aggression, screaming, agitation, wandering, sexual disinhibition, hoarding, cursing and shadowing. Psychological symptoms include anxiety, depression, hallucinations and delusions.

Understanding agitation

Some of the most common behavioural issues are that of agitation, wandering and aggression. In order to be able to assess, manage and treat agitation, it is of the utmost importance to investigate exactly what type of agitation is occurring and its description in detail. Agitation is further categorise agitation (*see Table 1*),[7] so that when someone presents with BPSD and delirium

Table 1

Categorising agitation

Category	Characteristics	Assessment
Physical aggressive behaviour	Slapping, kicking, hitting, punching, pinching, scraping	• Are they actively seeking others to strike or hit? This is extremely rare. • Is it arising due to resistance to an intervention? This is the most common cause • Has a delirium been ruled out?
Verbal aggressive behaviour	Abusive words or screaming at another person	• Is it directed at one particular person, gender, or is it during an intervention? • Has delirium been ruled out? • Has pain been ruled out?
Physical non-aggressive behaviour	Wandering, active, rummaging, restless behaviour without aggression	• What type of wandering behaviour is occurring? Look for a pattern • Are they under-stimulated? • Has delirium been ruled out?
Verbal agitated behaviour	Repeated vocal demands for attention, repetitive questions or statements that are not abusive	• Has pain been ruled out? Very common in this category • Is it due to the type of dementia? Some frontal lobe dementias can cause repeated vocal and physical behaviours • Psychological needs might not be addressed – calling out for comfort and attention may be exactly for that reason. Providing company and comfort can help

has been ruled out from assessment, the exact type of agitation can be identified.

Wandering

Wandering can also be further categorised to help identify what is happening.

Exit-seeking behaviour

This is the most problematic behaviour and involves many predisposing and precipitating factors, most often, a combination of loss of short-term memory and sundowning behaviour. The short-term memory of someone with dementia often means they don't have any memory of their house, which is usually the home they have lived in for most of their adult life – instead their long-term memories only allows them to recall the family home where they grew up. In the acute general hospital setting, wandering can pose a significant risk to PWD and is often placed on a 'special' or 1:1 for observation. Usually medication used at appropriate times in the afternoon and evening can help with this, as well as using reminiscence to help them feel in control and comforted.

Self-stimulation

This can often be mistaken for exit-seeking behaviour as self stimulators are people who were active their entire life and remain active into their dementia. Usually care approaches involve as previously mentioned using their long-term memories and finding out what it was they enjoyed or worked at when younger.

Sundowning

There is generally an increase in restlessness and wandering, confusion and irritability in PWD as the day progresses.[8] It is important to recognise when this is happening and appropriate psychosocial interventions and medication can help.

Aggression

Only 2% of aggressive events happen without an antecedent in dementia.[9] It is mostly the result of our interaction with PWD, their environment and the type of dementia they have. Aggression is most commonly caused when we are trying to get the PWD to do something (eg. get up, get dressed, eat, take medication). Aggression can also be the result of a delirium.

BPSD assessment of the PWD10

- Characterise the behaviour precisely with special attention to the circumstances in which it occurs. Were the changes gradual or sudden? Sudden changes in cognition or behaviour may be the result of a delirium – this must be ruled out
- Consider whether the patient has an underlying goal or if they are misperceiving their environment or the situation. They might feel like they must collect the children from school at a certain time each day when the children are now adults
- Review the patient's psychiatric history, social history and premorbid personality. If the patient was always active, they may continue to require a lot of activity in their dementia. If they were solitary, they may require a very low stimulus environment
- Review the medication list, including side effects, interactions, any new medications added recently. Check their drug toxicity and serum levels for certain medications such as digoxin and lithium
- Be vigilant of the ongoing progression of the patients dementia and the potential change in symptoms. Mood disorders (depression and anxiety) can predominantly occur in the milder stages of dementia, and challenging behaviour can occur predominantly in the moderate stages
- Examine the patient with attention to changes in mental status from baseline. Look for signs of painful/uncomfortable physical conditions. Pain can be a factor in challenging or resistive behaviour particularly when being moved or changed.

Behavioural observation sheets

Behavioural observation sheets allow us to obtain a more detailed picture of the BPSD occurring, and at the times of the day it's at its worst. Three days of using these can help identify patterns of behaviour, including: possible antecedents; times of the day; and sundowning behaviour. It can also provide an overall picture of the person's daily routine, including: eating patterns; activity periods; daytime sleeping; and sleep hygiene at night.

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References available on request from nursing@medmedia.ie (Quote: Flood, J Providing practical care for people with dementia. WIN 2013; 21 (1): 37-38)