

# Care planning and care management for people with intellectual disabilities and dementia

**W**ith improved social conditions, improved access to health care and advances in medical care, the life expectancy of people with intellectual disabilities (ID) has increased dramatically over the past number of years. Caring for this population involves two key areas: medical management and care planning. Contact between these two areas should be routine and ongoing, depending on the individual's needs.

Medical management will involve systematic treatment of all treatable medical conditions, such as epilepsy, sensory impairment or hypothyroidism. Treatment of these conditions should be as thorough as it is in the generic population. Co-morbid (accompanying) mental disorders (such as depression) should be treated appropriately. In particular, the treatment should be tailored to a clearly established diagnosis, rather than to vague behavioural symptoms, such as aggression. The use of neuroleptic medications for behavioural control should be limited to acute situations, and should be replaced whenever possible by appropriate behavioural, cognitive and environmental interventions. Indeed, the use of neuroleptic medication for clients with dementia can carry the risk of significant side effects and can more often be seen as a form of chemical restraint.

A comprehensive care plan with careful direction and supervision is essential when there is an overwhelming loss of personal care skills and mobility during the last stages of the disease. Ultimately, offering a specifically designed person-centred approach to care is crucial when working with people with ID and Alzheimer's disease. The individual may no longer be able to sit up, to walk, chew or swallow food, or control bladder or bowel. Added to these losses of function and general unresponsiveness, the person may develop the onset of epilepsy and is at a greater risk of infection. Given the total loss of body functions, the medical care team are responsible for deterring infections and promoting optimum quality of life. Care planning is as much an integral part of the wider process of providing dementia care as it is a feature in its own right.

## Challenges of care planning in dementia care

The label of dementia tends to prompt very negative stereotyped responses and consequently care plans tend to be viewed in terms of risk, dependency and disability. The low expectations of staff and carers, and the assumption that people with dementia cannot do much, leads to an enforced reliance and dependence on support.

Care planning calls for documenting and carrying out a treatment strategy appropriate to each stage of the disease. The general principles of care should include:

- ◆ Helping the individual to preserve and maximise function
- ◆ Using interventions and supports that are appropriate to the stage of the disease
- ◆ Conducting care planning that is multidisciplinary and involves information from multiple sources.

It is important to enable people with dementia to retain skills, strengths, preferences and relationships. Family, friends and staff are integral to the overall care management plan. They should be used as genuine

supports and encouraged to gain a better understanding of the nature and course of the disease. A balance should be maintained between providing supports that compensate for the loss of skills and encouraging the individual to perform activities that may preserve function. As the disease progresses, treatment practices need to be modified to meet the changing needs of the individual.

Care plans are essential for accurate record keeping and facilitate good communication, so that all members of the direct care team are singing from the same hymn sheet. They provide a framework for describing, defining and possibly quantifying a problem to ensure a common understanding amongst the professionals and carers who use them. They suggest strategies to address problems that arise. They provide consistency and continuity in care, and they give direction and help to set goals for the future. Overall, a comprehensive care plan will promote the best quality of life for the individual.

Care management involves structural activities such as making referrals for appropriate services, making environmental modifications, changing the general plan of care according to identified sustainable abilities of the individual. It involves individualised applications of clinical strategies to address problem management and carer concerns. The care plan is crucial in this step as it helps identify changes and personal care needs. It should be reviewed and evaluated regularly and modified to suit changing circumstances. Indeed, as the stages of the disease progress the needs of the person change dramatically, as should the care plan and care management.

Once the suspicion of dementia has been clinically confirmed, the individual's family or carers need to be made aware that changes need to be made in daily routine and the environment so that the person can feel safe and secure in his or her home/service setting. What may have been comfortable and appealing for the person in the past may be now unrecognisable, and consequently result in unpredictable behaviour. While the individual continues to remain mobile, their judgment may be decreasing, and he or she may be at risk of falling or wandering off. Under these circumstances, some of the person's responsibilities may need to be reviewed and modified.

## Important issues for the individual with dementia

Improve physical well-being (mobility)  
 Improve psychological well-being.  
 Maintain social functioning (ability to communicate)  
 Maintain levels of independence (self-care)  
 Ensure safety.

## Important issues for the carers

Improve psychological well-being (stress, emotional burden)  
 Improve knowledge skills (education, information)  
 Improve satisfaction (support/coordination of services).

## Assessment of need

It is well documented that the client with dementia must be involved in their own overall care, but with the progression of the disease there is a steady deterioration in memory and the ability to communicate—often the individual cannot articulate their needs anymore. A comprehensive

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assessment of needs is crucial. This may be assessed under the following headings:

#### *Neurological impairment*

Diminishing cognitive impairment, from a day-to-day care perspective, is a factor that must be accepted and worked with. Good medical diagnosis and ongoing monitoring are essential. In isolation, however, these are not sufficient for good care and practice.

#### *Physical health*

With increasing difficulty in communication this population are at increased risk of having their physical needs overlooked. Pain is an important issue affecting quality of life and an important goal in the care plan process for people with ID. It is estimated the one-third of those with dementia are in constant pain and more than half suffer severe pain. This population are less likely to report pain, therefore influencing the effectiveness of pain management strategies. Simple needs are also at risk (such as inadequate fluid intake, Constipation, agitation) all of which can influence behavioural episodes. If the physical problems of people with dementia are mismanaged, the physical factors exacerbate the symptoms of dementia.

#### *Biography*

All lives are shaped by background history and critical incidents in the past. Being aware of some of the losses and stresses experienced by people with dementia over their lifetime can be hugely beneficial. Collecting and sharing knowledge is critical for these individuals.

#### *Personality*

The personality of the individual has developed over his/her lifetime and is reflected in how that person reacts to stress. This will impact on how they deal with the experience of increasing loss of self and identity. As carers we must learn as much about these matters as possible to help us understand individual responses.

#### *Social environment*

The dynamics created by individual interactive styles can make a person feel valued or devalued. It is important to consider what people say and do, and how they say and do it have direct effects on the emotional well being of others. Therefore the social environment can support or undermine a person's sense of personal value.

#### *Personal and sensory environment.*

People respond to information from the physical environment by adapting their behaviour. This response is based on prior learning and recognition of the cues around them. For people with dementia the physical environment can be enabling or disabling, and it must be considered that dementia care is not about care of the dying; it is about meaningful life for the living. The sensory environment can be a powerful initiator of positive and negative behavioural responses and have a significant effect on the signs and symptoms of dementia. It is important to create a world within which people with ID and dementia can find comfort and pleasure, express their individuality, and rediscover human connection.

#### **Care plan content**

The values and beliefs we hold have a profound effect on

the way we think and behave. The mark of a good care plan is not that it is 'correct', but that it likely to lead to a better life for the individual. The following details should be in place for those with ID and dementia:

- ◆ Personal details
- ◆ Social information
- ◆ Preferences about food and daily life.
- ◆ The role of relatives and friends
- ◆ Health record
- ◆ Risk assessment for safety
- ◆ Manual handling and pressure sores
- ◆ Extent of confusion/challenging behaviour.
- ◆ Medication and medical treatment
- ◆ Any nursing care
- ◆ Self-care ability
- ◆ Help required
- ◆ Preferences about future care
- ◆ Religious/spiritual and cultural background.
- ◆ Advance directives—wishes about death and dying.
- ◆ Who is responsible for implementation (key worker)
- ◆ When it needs to be evaluated.

The following key elements should exist in the plan:

- ◆ Each care goal.
- ◆ How and when the goal is to be attained
- ◆ What strategies are to be tried
- ◆ Who is responsible for implementing each strategy
- ◆ When it needs to be evaluated

The care plan will provide a rounded picture of the client's self-help abilities, the aims of the individual plan, the essential ongoing care and level of support required, the outline of the usual daily routine and the client's own goals for the future.

#### **Care plan meetings**

These should be held every six months, or more often if necessary. The progression of the disease can often be rapid and the care plan will need to be regularly modified to accommodate ongoing changing needs. It is important that all people involved in the persons life is involved in the planning process. Unit staff, key worker, nursing staff, family members, the MDT, day services and, of course, the individual who presents with dementia. The members of the team must prioritise and set goals and needs for the individual.

#### **Conclusion**

Implementing the principles of the person-centred approach to dementia care is a powerful way to raise staff awareness of the needs of people with dementia. The care plan needs to be fluid and changeable. Periodic scheduled re-evaluation must take place, with changes being made as necessary. The ultimate goal of care planning is to guide all who are involved in the care of the individual to provide appropriate treatment, in order to ensure optimal outcomes. The key principle is positive action, which actively works to ensure that dependency and negativity is always minimised.

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