

The Needs of People with a Diagnosis of Dementia and Their Carers and Families

Authors : James Boag

Abstract : The needs of people with a diagnosis of dementia and their carers and families are physical, psychosocial, and psychological and begin at the time of diagnosis. There is frequently a lack of emotional support and counselling. Care- giving support is required from the presentation of the first symptoms of dementia until death. Alzheimer's disease begins decades before the clinical symptoms begin to appear, and in many cases, it remains undiagnosed, or diagnosed too late for any possible interventions to have any effect. However, if an incorrect diagnosis is given, it may result in a person being treated, without effect, for a type of dementia they do not have and delaying the interventions they should have received. Being diagnosed with dementia can cause emotional distress to the person, and physical and emotional support is needed, which will become more important as the disease progresses. The severity of the patient's dementia and their symptoms has a bearing of the impact on the carer and the support needed. A lack of insight and /or a denial of the diagnosis, grief, reacting to anticipated future losses, and coping methods to maximise the disease outcome, are things that should be addressed. Because of the stigma, it is important for carers not to lose contact with family and others because social isolation leads to depression and burnout. The impact on a carer's well- being and quality of life can be influenced by the severity of the illness, its type of dementia, its symptoms, healthcare support, financial and social status, career, age, health, residential setting, and relationship to the patient. Carer burnout due to lack of support leads to people diagnosed with dementia being put into residential care prematurely. Often dementia is not recognised as a terminal illness, limiting the ability of the person diagnosed with dementia and their carers to work on advance care planning and getting access to palliative and other support. Many carers have been satisfied with the physical support they were given in their everyday life, however, it was agreed that there was an immense unmet need for psychosocial support, especially after diagnosis and approaching end of life. Providing continuity and coordination of care is important. Training is necessary for providers to understand that every case is different, and they should understand the complexities. Grief, the emotional response to loss, is suffered during the progression of the disease and long afterwards, and carers should continue to be supported after the death of the person they were caring for.

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