

Early Onset Dementia

Ms RISHWORTH (Kingston) (21:11):

I move:

That this House:

- (1) recognises the devastating impact of early onset dementia on the lives of sufferers and their families;
- (2) notes that:
 - (a) individuals who suffer from early onset dementia often face unique challenges including obtaining an accurate and early diagnosis and finding appropriate accommodation and care facilities; and
 - (b) early onset dementia sufferers are generally still physically active, engaged in paid employment and many still have significant family responsibilities at the time of their diagnosis;
- (3) acknowledges that these characteristics often mean that sufferers of early onset dementia require support services tailored to their unique circumstances including:
 - (a) accommodation with appropriate support and activities specifically for their age;
 - (b) support for family members to understand and cope with the impact of the disease especially for young dependent children; and
 - (c) support for the individual and their families in managing their reduced capacity to work and inability to fulfil family responsibilities, such as parenting, as a result of the disease; and
- (4) calls on all levels of government to work together to appropriately support those suffering from early onset dementia and their families.

Dementia is often viewed by our society as an older person's disease and, while dementing illnesses such as Alzheimer's do generally affect older people, there are also many younger individuals under the age of 65 years being diagnosed with dementia. Access Economics has estimated that in Australia around 10,000 individuals have been diagnosed with early onset dementia. As I have outlined in my motion, the widely accepted correlation between dementia and the ageing process often means that individuals who suffer from early onset dementia face unique challenges and struggles throughout their illness. For this reason, I believe it is important that the House recognises the truly devastating impact of early onset dementia on the lives of younger sufferers and their families. For example, research shows that people with early onset dementia often experience significant difficulties in obtaining an early and accurate diagnosis. The younger population is more at risk of experiencing atypical dementias, which can mean that behavioural and personality changes are the obvious presenting symptoms rather than memory loss. Additionally, pronounced depression associated with the development of early onset dementia can mask the real illness because the two conditions share some symptoms such as a lack of energy and focus. The fact that younger sufferers often look fit and healthy also compounds the difficulties in obtaining an early and accurate diagnosis. This can be a long and frustrating process for sufferers and their families.

The motion notes that one of the significant challenges unique to early onset dementia sufferers and their families is finding appropriate accommodation and care facilities. Most services and facilities for people with dementia are designed for and targeted to older people and yet younger sufferers are generally still quite physically active and have significantly more energy, despite their dementia. As a result, younger sufferers who end up in aged-care facilities because their condition is no longer manageable in their family home often report feeling uncomfortable and out of place. What they really want is contact with other younger sufferers and activities tailored to their specific physical needs and personal interests. Many younger sufferers still want to be occupied in a meaningful way and have identified social activities, opportunities for volunteer work and supported employment, transportation and support for their families and young children as being most important to them.

The motion acknowledges that support is needed for family members to understand and accept the changing roles within the family structure as a result of this condition. There are some particular emotional challenges for younger sufferers diagnosed with early onset dementia. This debilitating condition can occur at a time when the person still holds multiple roles such as spouse, parent to young children or adult child to ageing parents. The impact of this shift in family structure on the individual sufferer is significant. In particular, suddenly becoming a dependent when you were relied on to take sole responsibility for things like paying the bills, driving them around and even feeding them can have a big impact. It is also very significant for their families.

As previously mentioned, those diagnosed with early onset dementia often have dependent children. While it is always upsetting at any age to watch the condition of a loved one suffering from a dementia illness deteriorate, children can find this even more difficult as they struggle to comprehend what is happening to their parent. Children of parents diagnosed with early onset dementia often feel confused, frightened at the gradual loss of their parent's memory and by the prospect that they too may suffer from this disease and anxious as a result of the added strain placed on their parents' relationship. Children may also feel isolated as their well parent's time is increasingly taken up with caring responsibilities.

I rise to speak on this motion tonight because of one particular family I met in my electorate. I would like to mention Jenie Aikman and her husband Kym, who was diagnosed with early onset dementia approximately three years ago at the age of just 41. Kym can no longer live in the family home. Jenie said to me: The services and facilities are all targeted at older people with dementia. I had to be a full time mum and a full time carer but I wasn't even entitled to the same assistance that carers are when the sufferer is 65 years and over. Sadly, this means that you are forced to put your loved-one in an aged care facility sooner. This is an issue to do with early onset dementia that we must pay attention to. I commend the motion to the House.