

## **STRATEGIES TO SUPPORT INFORMAL CARERS OF PEOPLE WITH DEMENTIA**

Thank you for the invitation to speak to you about strategies to support carers of people with dementia.

Alzheimer's Disease International (ADI) ADI is the international federation of Alzheimer associations around the world. ADI seeks to strengthen and support Alzheimer associations in 94 countries, to raise awareness about dementia worldwide, to make dementia a global health priority, to promote access to support and care, and to increase investment in dementia research.

Informal carers include family members and partners, friends and neighbours. Commonly, in high income countries over 70 per cent of people with dementia live in the community, with much of the care provided by informal carers. In low income countries, in the absence of services the percentage will be nearer to 100 per cent.

Policy in respect of informal carers is given a priority although the rhetoric is often not matched by the funding required. Support for informal carers is recognized as a priority area for action in the Global Dementia Action Plan and the target by 2025 is for 75% of countries to provide support and training programs for carers and families of people with dementia.

In the 2015 World Alzheimer Report, ADI presented estimates of the global societal economic impact of dementia. The global costs then were estimated to be US\$ 818 billion, a figure now (2018) surpassing US\$ one trillion per year. Of these costs:

- 40% were related to informal care,
- 40% to the social care sector and
- 20% to the medical sector.

In the report Global Estimates of Informal care ADI estimated that the annual global number of informal care hours in 2015 provided to people with dementia living at home was about 82 billion hours, equating to 2,089 hours per year per person with dementia or 6 hours per day. This is the equivalent of more than 40 million full time workers in 2015, a figure that will increase to 65 million full time workers by 2030.

Women contribute to 71% of the global hours of informal care, with the highest proportion in low income countries who have 68% of the world's population of dementia.

Strategies to supporting informal carers are:

1. Timely diagnosis and post diagnostic support
2. The service and support needs of informal carers
3. Making the informal carer a care partner

#### 4. Reducing fragmentation and increasing the flexibility of service delivery

Strategies to support informal carers of people with dementia is made the more complex by societal changes already in progress all over the world. These include shifting family structures, migration and the increasing participation of women in the workforce. This scenario presents a great challenge for society in terms of financing, training and flexible workplaces.

#### **Diagnosis and post diagnostic support**

The journey with dementia is unlikely to start well for the carer or the person with dementia if the diagnosis of dementia is not timely or does not include referral to support. Even in high income countries less than 50% of people dementia receive a diagnosis and it may take on average 30 months to establish. For the carer there is the added drama of often not being accepted as a partner in the diagnostic process by the doctor. And worse still there is often poor communication of the diagnosis and no referral to Alzheimer organisations or others that might provide information and support.

The Global Dementia Action Plan in action area 4 requires that ***in at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025.*** That is a welcome and ambitious target.

Scotland has gone further and established a right to post diagnostic support to assist the carer and the person with dementia plan future care and support. Without that right and an identified support person it is probable the carer and the person with dementia will either be lucky in their doctor or remain ignorant of where to go next for support.

#### **The service and support needs of informal carers**

While the caring role can have positive benefits, the common consequence is an experience of loss. Carers of people with dementia will spend many hours per week assisting with the range of activities of daily living and are negatively affected by care-giving in terms of impacts on employment, finances, family, psychological and physical health, and leisure time.

Dementia care is particularly stressful because of the changes in the person's cognition and abilities, behavioural and emotional changes and changes in the relationship between the carer and person with dementia including a sense of loss. In addition, stress may be caused by the impact on the carer's activities, conflict and strain in family relationships and financial strains.

This stress is made all the more difficult by the social isolation and stigma that informal carers report as a consequence of a diagnosis of dementia. The context in which support for informal carers is provided is unlikely to be positive unless there is a commitment from governments to tackle dementia through dementia plans that include action on increasing awareness of dementia, protecting the rights of people with disabilities and promoting dementia friendly projects that enable people with dementia to access to services and activities we all enjoy.

The service responses take many forms.

First, informational support that provides resources on dementia such as the various types of dementia, memory loss, diagnosis, genetics, risk factors, medications and assistive technologies. Many resources are available on Alzheimer websites around the world and the WHO have recently produced iSupport, an excellent online training program for carers of people with dementia.

Second, support to assist with the activities of daily living of the person with dementia such as bathing, dressing, functional mobility and feeding. Assistance may be available too with the instrumental activities of living to assist the person with dementia to live more independently in their own home such assistance with housework, preparing meals, shopping, transport and personal care.

Third, respite care and day centres. Respite care has been traditionally thought of as relief for the carer, but it needs to be designed to benefit both the informal carer and the person with dementia. It can take many forms – emergency, in home, day centres.

Lastly, meeting the health and psychological needs of the carer. A high proportion of family carers have psychological disorders while others may have symptoms. These reduce carer's quality of life and increase the likelihood of the person with dementia moving to residential care as the carer becomes unable to care. These services may take the form of support groups and counselling, education about dementia, care giver issues and problem solving and psychological interventions such as cognitive behavioural therapy.

The effectiveness of these services will be dependent on the approach taken to carer assessment and on collaboration to improve care access.

### **Assessment of the needs of informal carers**

Assessing the needs of informal carers is complex because the needs of each will be unique. In addition, informal carers may be reluctant to seek help and have changing needs as the dementia progresses.

Carer assessment needs to be sensitive not only to physical needs but the relational dimensions of dementia. These are particularly evident in the complex interdependencies inherent in care giving and the dynamics of changing relationships as the person with dementia requires increased support in carrying out activities of daily living and support in decision-making.

Unless the assessment process is person centred on the needs of the informal carer it is unlikely that there will be a full understanding of past and future relationships and the support or services needed to meet their needs and those of the person with dementia. In short, to treat the informal carer as partner and expert. The requirement is not to give services to informal carers but rather to negotiate with them.

One approach to achieving a negotiated outcome with the informal carer as partner is the Carers Outcome Agreement Tool (COAT). It has shown significant potential benefits in encouraging both service provider and informal carer to think outside the box. Other researchers have drawn attention to areas of concern relating to the greater expense in respect of more practitioner time and may be the generation of false expectations.

### **Reducing fragmentation and increasing flexibility of service delivery**

Having determined the needs of the informal carer an even greater challenge is to ensure services are accessible. There are multiple strategies.

Case managers may be necessary to achieve the collaboration in more complex cases. In less complex cases an identified support worker post diagnosis or at other times may assist in access to services or providing information on services.

Other approaches recognize the need for a multi-faceted approach. The Resources for Enhancing Alzheimer's Caregivers Health (REACH) adopts such an approach to targeting depression, burden, self-care, social support and problem behaviours in the person with dementia. Intervention strategies include education, stress and mood management techniques, communication skills, and problem solving delivered in 12 sessions over 12 months.

The Care of People with dementia in their Environments (COPE) program is a structured occupational therapy and nursing intervention for people with dementia and their caregivers living at home. COPE aims to support and empower people with dementia and their carers to independently manage everyday difficulties. It has proven effective in reducing dependency and increasing engagement in the person with dementia and improving carer wellbeing.

Some countries have empowered the carer by giving them a budget to use or having cash instead of service to buy the services they require.

In other countries such as Japan the focus has been on service flexibility and ensuring that services like respite and dementia day care centres are available 24/7

### **Translating research into practice**

Arguably, there is a large body of experience and research on the needs of informal carers and evidence to suggest the interventions are valued and effective. Questions exist about the sustainability of the benefits beyond the programs. It seems though that access to such interventions is limited and that there are barriers to translating the outcomes of experience and research into practice even where the evidence is strong. Possible reasons identified for this are the difficulty of translating findings into a health and service environment, a lack of confidence in staff in working with the complex symptoms of dementia, lack of government funding and the meeting the diverse needs of different populations.

### **Conclusions**

Policy priority is being given to support the informal carers but not always the funding!

Strategies to support informal carers of people with dementia will require:

- A change to the way the community thinks about dementia to reduce stigma and social isolation
- Recognition that the needs of informal carers are multiple and will change over time.
- Carer assessment that is person centred
- Collaboration and service flexibility to improve access to services.
- More funding and research are a priority but so too is knowledge translation.