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“We don’t question whether people with cancer need treatment” – New report finds as many as 85 percent of people with dementia could be missing out on post-diagnosis care

- *Dementia experts call for dementia care after diagnosis to be recognised as a human right*
- *Planned post-diagnosis dementia treatment, care and support are vital to improving the quality of life for people with dementia and for those who care for them*
- *Alzheimer’s Disease International (ADI) urge governments to implement robust post-diagnosis care plans into national dementia planning*

LONDON - 21 September 2022: In response to new data showing that, appallingly, up to 85 percent of the over 55 million people living with dementia may not receive post-diagnosis care, world-leading dementia experts are calling for dementia post-diagnosis, care, treatment and support to be recognised as a human right.

Alzheimer’s Disease International (ADI), the international federation of 105 Alzheimer and dementia associations around the world, is today releasing the *World Alzheimer’s Report 2022 – Life after diagnosis: Navigating treatment, care and support*, which was co-authored by McGill University.

The report focuses on the urgent need for significant improvements to essential post-diagnosis treatment, care and support services for the over 55 million people living with dementia across the globe and robust plans to support the forecast 139 million people by 2050.

Post-diagnosis dementia care, treatment and support refers to multiple interventions that can improve the quality of life for those with dementia, including both pharmacological and non-pharmacological treatments, caregiving, access to healthcare, support for daily life activities, home adaptations, social inclusion and respite.

“We don’t question whether people with cancer need treatment, so why is it that when people receive a dementia diagnosis, they’re often not offered treatment or care? Repeatedly, they’re just told to get their end-of-life affairs in order,” says Paola Barbarino, ADI CEO. “Coupled with improving diagnosis rates, post-diagnosis dementia care must be recognised as a human right.”

“While dementia doesn’t yet have a disease-modifying ‘cure’, there is clear evidence that demonstrates that appropriate post-diagnosis treatment, care and support significantly improves the quality of lives of those living with this disease, allowing many to maintain independence for longer.”

Roger Marple, a Canadian living with dementia and author of an expert essay within the World Alzheimer Report, emphasizes that a dementia diagnosis isn’t the end of the road for people living with the condition.

“After my diagnosis, I heard things like ‘Why should we do anything about dementia care? They [people with dementia] are just going to die anyway’. These sorts of comments are incredibly demotivating,” says Marple. “We all live with a terminal condition – it’s called life. In my world, it is all about the *quality* of life regardless of any challenges we live with. Before there is a cure, there is care; never forget that.”

The pressure on global healthcare systems during the pandemic has further exacerbated the ability for healthcare professionals to provide adequate post-diagnosis treatment, care and support for people living with dementia.

“Part of the issue is that 62 percent of healthcare professionals wrongly believe dementia is a normal part of ageing, with this belief fuelling the lack of support offered to people living with

dementia,” says Barbarino. “Another part is that healthcare systems around the world are not prepared for the growing public health crisis that dementia presents, and governments must act.”

Of the healthcare professionals surveyed in the *World Alzheimer Report 2022*, 37 percent said that they feel stressed or under pressure often or all of the time with a quarter of these professionals reporting this impacted their ability to do their work. 59 percent said they do not feel they have adequate time to provide care for a person living with dementia.

Barbarino says that she’s sympathetic to the pressure that healthcare professionals are under, and governments must invest to support them as the world cannot afford to let post-diagnosis dementia treatment fall to the wayside.

“Globally, clinicians are both under-educated on dementia, and under-resourced to provide adequate post-diagnosis care for people living with dementia,” says Barbarino. “It’s up to governments to shore up their healthcare systems so that it’s possible for healthcare professionals to provide quality care that people living with dementia desperately need.”

Barbarino continues “But as it stands, the care model where a primary care doctor hands over long-term post-diagnostic support to other specialists is untenable due largely to the shortage of such specialists and the ever-increasing numbers of people living with dementia. Every three seconds someone develops dementia”

“Life doesn’t stop at a diagnosis for people living with dementia. It’s an ever-evolving condition that can last throughout many years,” says Barbarino. “People living with dementia, their carers, and their care team need to regularly update and adjust their skills and knowledge to ensure high-quality ongoing care.”

The United Nations already recognises dementia as a disability and as part of ADI’s call for post-diagnosis care to be recognised as a human right, ADI are urging governments across the globe to incorporate post-diagnosis care into their national dementia planning.

“Approximately 139 million people are expected to have dementia by 2050. For many of those people, the responsibility of post-diagnosis care will fall on their family carers, and it can’t be up to them alone,” says Barbarino. “Governments around the world must invest in healthcare professionals, treatment and caregiving strategies while the world awaits new technologies to diagnose and treat dementia.”

ADI recommend that a first step governments can take should be committing to identifying a trained ‘navigator’ to act as liaison for a newly diagnosed person with dementia, to enable them to connect and engage with the vital supports and services they need.

“It greatly improves the quality of life for a person with dementia if they have clear access to health resources, care, information, advice, support, and importantly life adaptations and adjustments,” says Barbarino. “Ensuring these navigators can act as a single point-of-contact for people living with dementia could be the key to helping navigate this incredibly complex journey”

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About Alzheimer's Disease International (ADI)

ADI is the international federation of 105 Alzheimer associations and federations around the world, in official relations with the World Health Organization. ADI's vision is prevention, care and inclusion today, and cure tomorrow. ADI believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge. ADI works locally, by empowering Alzheimer associations to promote and offer care and support for persons with dementia and their care partners, while working globally to focus attention on dementia and campaign for policy change. For more information, please visit www.alz.co.uk

Case studies

Emily Ong, Singapore, diagnosed with young onset dementia at age 50 tells us clearly why there is a need for immediate post-diagnosis care planning based on an all-too-common struggle. "I spent the majority of my initial two years post-diagnostic phase in a state of a constant panic attack. Almost every other day, I would experience palpitations, cold sweat, uncontrolled clenching of the teeth and contractions of jaw muscles, hand tremors, nausea, the unexplained piercing pain in my head which was unlike the typical migraine or headache I experienced, and avoidance of going to crowded places, common signs and symptoms of anxiety."

Keith Oliver in the United Kingdom said, "My care plan took me four years to achieve and 15 minutes to write in a consultation appointment with my consultant psychiatrist."