

Dementia: post-diagnostic care and support

Published 8 January 2016

Joint declaration on post-diagnostic dementia care and support

Why a declaration?

Once a person with dementia has received a diagnosis it is essential that they get appropriate post-diagnostic care throughout the course of their life, with the period immediately following diagnosis being a critical time for this to occur. This is needed to ensure that people living with the effects of dementia and their families and carers have the right information and support so they can live as fulfilling lives as possible, prepare for the future and their preferences for end of life are acted upon.

Post diagnostic support for people living with the effects of dementia and their families and carers should be personalised, flexible, culturally relevant and have proper regard to equality. There is no one size that fits all, with different needs existing according to personal wishes and circumstances, the nature of the dementia and the course of the condition. The whole person needs to be considered, taking into account any co-morbidities, allowing them the opportunity to have the choice and control to manage their condition as far as possible and to live as well as possible with dementia.

The person with dementia and their close family and carers should be able to talk things over with relevant services and professionals and be fully supported. At present, the quality of post diagnostic care, including access to carer support, is variable according to where an individual lives and the availability of local services - this must change. All people living with the effects of dementia and their families and carers should receive high quality support and information, available at the point of diagnosis, through the period following a diagnosis as their condition progresses and to the end of life.

This declaration sets out:

- our shared commitment to joint action across government, health, social care, the third sector and all other relevant partners
- our ambition to deliver better quality post-diagnostic care
- the need to deliver integrated and effective services that meet the needs of people with dementia and their families and carers

Working together our ambition is to ensure that:

- the views of people living with the effects of dementia and their families and carers are taken fully into account when determining the nature of post-diagnostic services offered, with high quality personalised care provided in line with individual needs and preferences
- access to holistic, integrated and effective post-diagnostic support is available for all, which takes into account age, ethnicity, diagnosis and co-morbidities
- the health, physical and emotional needs of families and carers are fully recognised, and their views are taken into account, especially at times of change
- families and carers are supported by receiving appropriate information and training on caring for someone with dementia and given access to appropriate support to meet their needs
- people living with the effects of dementia, their families and carers, as well as health, social care and third sector professionals, are aware of what local services are available and how to access them, to enable people to live and die as well as possible with dementia
- appropriate evidence is available across health and social care on best practice in post-diagnostic care, what best meets people's needs and what initiatives are cost-effective
- all professionals in health, social care and the third sector who support people with dementia have appropriate information, knowledge and understanding of the condition and what constitutes good quality post-diagnostic care services
- appropriate dialogue takes place on making the best use of resources to ensure that services are available
- partners across government, health, social care, the third sector and all other relevant agencies cooperate and collaborate to improve outcomes for people with dementia
- health and social care services are coordinated and fully integrated to meet the post-diagnostic needs of people with dementia and their families and carers
- people living with the effects of dementia and their families and carers are made aware of and given the opportunity to participate in relevant research