

Worksheet 16:

Recognition for carers

The **Global Dementia Charter** of 2013, published by Alzheimer's Disease International, identified ten key areas from the perspective of a person with dementia which would enable them to live well. Three of these points are concerned with the needs of their family, friends and carers too:

- ✓ I SHOULD HAVE ACCESS TO INFORMATION ABOUT DEMENTIA SO I KNOW HOW IT WILL AFFECT ME. Dementia will affect me and everyone around me. My family, friends and I should have access to high quality information and advice so we know what to expect as my condition progresses.
- ✓ I SHOULD BE HELPED TO LIVE INDEPENDENTLY FOR AS LONG AS I CAN. I want to be as active as I can, for as long as possible, supported by those around me, in a safe environment.
- ✓ I WANT MY FAMILY AND FRIENDS TO HAVE FOND MEMORIES OF ME. I want to have peace of mind that my family and friends will have adequate support to cope with my death and be comforted in their grief, to help them remember me for the person I was.

The **Alzheimer's Society** document '*Dementia 2012: A national challenge*' also references what people living with dementia have advised regarding the recognition and support of their family carers: "*My carer can access respite care if and when they want it, along with other services that can help support them in their role*".

The **National Institute for Health and Care Excellence (NICE)** published the 'Quality Standard for Dementia' in 2013. This guidance is described as "*a person-centred and integrated approach to providing care and services (which) is fundamental to delivering high-quality care for people with dementia. The quality standard acknowledges the vital importance of involving carers of people with dementia. Services should consider how to ensure carers are involved in the implementation of each quality statement*". To this end, eight of the ten quality statements include reference to the involvement of carers.

The '**Prime Ministers Challenge on Dementia 2020**' was published by the Department of Health in England in 2015. This document built upon the 'Prime Minister's Challenge on Dementia 2012' and set out the Government's aspirations for all those affected by dementia. Regarding carers, the document stated that "*by 2020... carers of people with dementia... [should be] made aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring*".

The **World Health Organisation (WHO)** also recognises the contribution carers make to the lives of people with dementia. WHO has created iSupport, a knowledge and skills training programme for carers of people living with dementia, and in July 2021 WHO released '*Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives*', which aims to support countries in establishing, scaling and evaluating dementia-friendly initiatives to foster societies where people with dementia and their carers can meaningfully participate.