Advance care planning in dementia

Having emotionally difficult conversations is just one challenge for people with dementia and their care partners when engaging in advance care planning (ACP). The conversation could make people feel as if they are dying, or feel that the inevitable cognitive deterioration associated with dementia is too frightening to think about in advance. Some people might perceive documenting a person with dementia's preferences for specific future treatment as threatening their autonomy.[1] In one of very few studies conducted in acute care, care partners were willing to discuss future care yet unwilling to write plans.[2] However, care partners might regret not having had such conversations when the person was still able.[1] They also might not have been alerted early enough, as health-care professionals might dread emotionally difficult conversations. However, an expert in our Delphi study found that "dementia is a terminal condition; to avoid this reality does patients a disservice".[3]

"Persons with dementia and family should be offered the opportunity to engage in ACP shortly after diagnosis" while "ACP on end-of-life care should be tactfully introduced, explained and offered at a follow-up consultation".[3] This distinction is because ACP can be crucial for people with neurological disease, who often face reduced capacity and communication as their disease progresses.[4,5] A flexible approach is helpful in providing the right information and exploring the person's preparedness to engage in ACP.

ACP conversations should become an integral part of routine clinical practice of neurologists, gerontologists, family doctors, and multidisciplinary teams involved in the care of people with dementia. These conversations should be encouraged, even if families and professionals initially fear that people with dementia might not cope with the issues or become anxious or depressed. If undertaken with care, and often over a period of time, the person can be involved. When unable to decide for themselves, due to declining capacity or general deterioration and weakness, their care can then be aligned to their preferences. Initiation of these conversations by the neurology team in the early stages of dementia allows for the greater involvement of the person in their care. This personalised approach to ACP will benefit all involved: the person with dementia, their family and carers, and the professional team.

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AFRICTRIMS: a step towards broadening multiple sclerosis conversations

In 2024, the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) congress celebrated a remarkable 40 years of pioneering work. Regional committees have emerged around the world, but there has been a glaring gap on the African continent, until the foundation of the African CTRIMS (AFRICTRIMS).

Multiple sclerosis and related diseases have been thought not to exist in Africa due to a lack of awareness, specialists, diagnostics, and access to disease-modifying therapies.[1] Some of these factors are now being addressed through new local patient support groups and neurology training programmes, and by research highlighting local epidemiology and unique phenotypes.[2]

Inspired by other regional CTRIMS, in particular by the exemplary Middle East North Africa CTRIMS,[3] the idea of AFRICTRIMS came from growing collaborations between physicians in the region, driven by the need to provide adequate care for people with multiple sclerosis. These connections were further strengthened during our second multiple sclerosis conference in Nairobi in 2023,[4] and the network has helped improving access to diagnostics and treatment for patients across borders. In 2024, we held a successful online workshop aimed at training health-care professionals involved in the management of patients with multiple sclerosis, from ophthalmologists to spinal surgeons. In August 2024, we launched a monthly AFRICTRIMS webinar series to encourage the dissemination of new local and international research, facilitate discussions of complex cases, and foster connections to and between patient support groups.[5]

We have many other goals and aspirations for AFRICTRIMS in the coming years, such as attracting renewed interest from pharmaceutical companies to conduct multiple sclerosis clinical trials in Africa and helping to prepare more hospitals across the continent, particularly in sub-Saharan Africa, to be clinical trial