# Whole Systems Dementia Treatment: An Emerging Role in the NHS?

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### INTRODUCTION

Alzheimer's disease (AD) is increasingly understood as a disease state determined by multiple factors and mechanisms. Besides the usual risk factors of diet, exercise, cognitive stimulation and sleep hygiene, one recent review lists a wide range of other risk factors.1 Although nonpharmacological treatments for dementia are perhaps less known among medical practitioners, the latest NICE guidance calls for these as a first point of call.<sup>2</sup> An integrative, complementary or 'whole systems' approach is designed to activate the body's inherent healing mechanisms and treat the root cause of illness as well as associated symptoms.3 Dementia often precedes other chronic conditions such as diabetes and heart disease, and improves through similar pathways of diet and lifestyle changes. Therefore, targeting the causative factors for dementia would have the added benefit of addressing more broadly a wide range of common morbidities in older adults. We aim in this paper to introduce the concept of multimodal treatment for dementia (MT4D), share evidence from the literature including case studies, identify precedents and a transformation agenda in the NHS, summarise initial and current practices in the Memory Assessment Service (MAS) and describe research proposing whole systems dementia treatment.

### **MULTIMODAL APPROACHES**

Findings from a recent systematic review of multimodal non-pharmacological interventions to improve cognition for people with dementia<sup>4</sup> identified a diverse combination of interventions, including cognitive enhancement therapies, physical exercise and rehabilitation, psychological and psychosocial therapies, nutrition and diet, sleep hygiene, stress reduction, detoxification, hormonal health and oxygen therapy. In 90% of the studies, participants were reported to have cognitive improvements, stability with their dementia or a delay in their decline. The case studies were of particular interest as the practitioners used in-depth assessments and prescribed up to nine different therapeutic modalities.

One case study from the USA reported an individualized Alzheimer's treatment protocol which reversed cognitive decline in 10 patients with mild cognitive impairment, memory loss and early AD.<sup>5</sup> This novel therapeutic approach enhanced patient metabolism through diet, exercise, improved sleep, stress reduction, cognitive stimulation, vitamins and supplements.<sup>6</sup> A biomedical examination included checking for genetic risk factors, hormone and dietary deficiency, metal toxicity, infections, mold, Lyme disease, etc. For most of these patients, the author maintained improvements began within 3 months.

A further case study in Spain involved a 78 year old female who:

"suffered mental decline for about 1 year. She could no longer conduct her usual activities and home chores and could not hear without a hearing aid. Brain magnetic resonance imaging (MRI) performed in February, 2008, revealed degenerative changes. Treatment consisted of repeated sessions of intermittent hypoxic training (IHT), and individualized vitamins, amino acids, microelements, supplementation, and nutritional adjustment. Until April, 2009, the patient had completed four cycles of IHT and 8 months of the supplementation program. The patient gradually recovered her healthy mental state; she resumed shopping and cooking and began playing piano again, which she was not capable of doing last year. An MRI of her brain performed during April, 2009, showed no degenerative changes.'

Some have argued that nutritional, botanical, and stimulatory therapies may provide more benefit and with fewer adverse consequences than conventional medications.<sup>8</sup> But opportunities also exist for adjunct therapies that could assist and enhance the normally prescribed pharmaceutical treatments. For instance, recent studies have shown the efficacy of multimodal interventions as adjunct therapies for stable doses of memantine, cholinesterase inhibitors or antidepressants.9-10 One Italian study reported on 50 patients with probable AD during a comprehensive rehabilitation programme in a specialized hospital unit for an average of 26 days. The primary therapy was Reality Orientation Therapy (ROT) integrated with individualised cognitive approaches, plus psychotherapy and/or physical therapy as needed. Significant effects were found on cognitive and functional outcomes, suggesting that a combination of therapy, rehabilitation, support and medication may be useful.<sup>11</sup> Because dementia is complex and multifactorial, early interventions that target multiple risk factors are most likely to be effective.

### PRECEDENTS IN PRIMARY CARE

Integrating complementary treatment methods into the NHS has shown beneficial outcomes. For instance, statistically significant fewer antibiotics were prescribed through Integrative Medicine (IM) approaches being taken in GP surgeries. Complementary and integrative interventions such as diet, exercise, cognitive training, and vascular risk monitoring utilized in primary care may preserve cognitive function. A recent review of complementary and integrative gastroenterology found that: polyphenols including curcumin, resveratrol and epigallocatechin-3-gallate (EGCG), have supportive data for the treatment of ulcerative colitis (UC) flares; yoga has beneficial effects on symptoms, anxiety and physical

functioning for patients with IBS; and a large randomized trial demonstrated superiority of melatonin and nutritional supplements compared with omeprazole for reduction of gastroesophageal reflux disease (GERD) symptoms.<sup>15</sup> In terms of providing emotional and psychological as well as cognitive support while developing positive lifestyle change, a holistic health group intervention (holistic brain health approach plus an Eastern approach to health care) resulted in significant cognitive and memory improvements compared to controls.<sup>16</sup>

#### TRANSFORMATION AGENDA IN THE NHS

Although complementary approaches remain unlikely to be provided solely through the NHS, nutrition, physical activity, mindfulness, and stress management appear in the NHS Living With and Beyond Cancer agenda. Wholeperson oncology care describes an approach that addresses the needs of the person as well as treating the disease.<sup>17</sup> It involves giving people the skills, therapeutic support, and confidence they need to boost their resilience and manage the symptoms, alongside treatments that help them live as well as possible, for as long as possible. Interventions under this initiative and others have brought positive impact to patient health and ability to sustain positive behaviour change. Some cancer charities for instance, provide support, information, and complementary medicine (eg, mindfulness, acupuncture, natural products). Examples such as Penny Brohn UK and Maggie's Centres work with the NHS to provide self-management education and complementary therapies. Promoting self-management and lifestyle support are at the heart of the Government's sustainable healthcare transformation agenda.

## THE NHS MEMORY ASSESSMENT SERVICE (MAS)

Prior to the MAS, old age psychiatry services cared for patients with memory problems (termed 'senile') either through inpatient services (patients suffering mental illness and confined to a psychiatric hospital), or in community services (cared for at home by family). In 2009, Living Well with Dementia: A National Dementia Strategy came on the back of an international push to identify dementia and recognise its prevalence. The strategy recognised the advantages to quality of life that an early assessment and intervention can have for people with dementia and their carers and sought to guarantee access to that support through a memory service. These were expected to meet quality standards by providing at least 'comprehensive diagnosis and assessment of memory problems and followup' as well as information, counselling and supportive work, and ideally a range of interventions, health promotion, treatments, teaching, training and links to local services, among other provision.<sup>18</sup>

The initial management of AD, as a type of dementia, was to prescribe an acetyl-cholinesterase inhibitor (such as Donepezil) and to support the family. For vascular dementia, emphasis was on lifestyle, reducing blood pressure and cholesterol, and controlling blood glucose. GPs were advised to consider prescribing anti-coagulants

to cardiac risk patients (if patient is not on anti-coagulant as prophylactic) and to reduce cardiac risk factors.

### Current Practice at the Lancaster-Morecambe MAS

Occupational Therapists (OTs) help patients to remain longer in their homes by assessing occupational performance, or making an activity analysis in areas where cognitive function is evident in everyday tasks. In tandem with social care, OTs place emphasis on support and encouragement through technologies, aids and strategies, or some degree of environmental adaptation within the home. A patient is encouraged to remain independent and carry on their usual enjoyable activities, maintain a social life, do something creative, take gentle exercise or participate in gardening, baking or singing groups to improve self-esteem and reduce loneliness. For advanced dementia, a multi-sensory approach is suggested which stimulates the person through sounds, colours, lights, fragrance and tactile objects.

Cognitive Stimulation Therapy (CST) involves group activities and exercises designed to improve memory, problem solving skills and language ability. A monthly drop-in wellbeing session hosted at the MAS offers opportunities to engage in cognitive stimulation activities, supported by recent NICE guidance.<sup>2</sup> Through copartnership with the Alzheimer's Society, a representative is on hand for informal discussion, along with a member of MAS clinical staff to address specific questions about medication or diagnosis and to signpost people to further resources.

Self-care involves taking responsibility for one's own health and wellbeing with the support of those involved in a person's care. Support can be found at dementia cafés, many facilitated by the Alzheimer's Society and offering activities, advice and refreshment. Cafés can provide practical and emotional support, information and guidance.

Along the patient pathway, a post-diagnostic session is given during which lifestyle factors might be suggested. A discussion with the patient and their family member or friend, may range from the importance of a healthy diet to improving sleep patterns. If psychological health is an issue then mindfulness might be recommended, or encouragement to share emotions and feelings. This holistic approach of the MAS is compatible with whole systems treatment.

Although there is care and support for people with memory problems, there is little investigation to address the root causes of a person's cognitive decline. Socializing, reminiscing, art, singing and so on are of obvious benefit to improve quality of life, including that of caregivers. However, personalised recommendations for diet, exercise, stress reduction, sleep hygiene and detoxification based on root-cause investigation show efficacy by actually delaying the steady decline – an approach not taken previously. But now, with evidence emerging that symptoms can be reduced, delayed and in some cases reversed with a personalised medicine approach, there exists the capability of a further step-change in memory services, from living well *with* dementia, to living well *beyond* it.

## A PROPOSAL FOR WHOLE SYSTEMS INNOVATION

Based on prevalence rates and population projections, the number of individuals living with dementia in the North West is expected to rise to 69,025 by 2020, placing significant pressures on services and communities.<sup>20</sup> One approach to improve patient and caregiver outcomes and delay long-term care would be to apply current evidence towards treating the root causes of the condition. Some GPs trained in integrative or functional medicine (I/FM) would like to bring such treatment to patients in their NHS setting. The difficulties are numerous: this approach requires specialised medical training and experience on top of traditional medical education; is time-consuming with 60-90 minute appointments plus multiple emails; needs 'coaching' support for lifestyle-change of the patient and requires some blood tests that the NHS does not routinely order. In a typical protocol, a practitioner might investigate inflammation, toxicity, poor GI health, nutritional deficiencies and dietary insults (gluten, sugar) and then prescribe accordingly.

Encouraged by the recent evidence review of multimodal treatments for cognition,<sup>4</sup> research is underway to develop a novel treatment approach for subjective or mild cognitive impairment (SCI, MCI) or early dementia by the Centre for Ageing Research (C4AR) at Lancaster University, supported by the Lancaster and Morecambe Bay MAS and referring GPs. An intervention protocol compatible with the existing patient pathway was developed whereby root cause investigations will be carried out by I/FM GPs following routine memory services. While a multidomain trial in primary care for atrisk community-dwellers was proposed in Australia,<sup>21</sup> this currently proposed study is unprecedented in the UK.

A further aspect might be health coaching by trained volunteers. Previously, Milders et al.<sup>22</sup> demonstrated in six NHS surgeries how an intervention could be more sustainable, accessible, cost-effective and reduce demands on health services by involving trained non-professionals to present a multi-component intervention for caregivers and people with dementia. Whilst individual interventions have proven cost-effective,<sup>23</sup> an economic evaluation of this multimodal strategy would be included in this research.

In 2019-2020, this feasibility study will involve the Lancaster-Morecambe Bay area, leading subsequently to a controlled trial across the UK. A protocol for multimodal treatment would entail educational talks and workshops covering holistic approaches to healthy ageing. These would be held in proximity to an outdoor nature-rich social space (community garden/nature reserve, sports or recreation area, etc.) where participants would be supported to join in year-round activities. Discussions are currently underway to enlist partners and garden sites, refine the protocol and seek research funding. Your comments and suggestions are encouraged.

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# Shock horror! Volunteer amateurs administer medication! David Handley

Relax, this piece is about volunteers feeding patients acknowledging that food is medicine and a vital part of recovery.

Most hospitals encourage friends and relatives to feed patients who require such help. This takes the strain off other ward staff. Best friends and relatives are not always to hand, thus the value of volunteer meal time assistants known sometimes as 'feeding buddies'. My experience, over several years, is on an orthopaedic ward where patients are often elderly, sometimes confused after a fall or break and involving one or another of the limbs.

The problem is this; appetite gone, appetite reduced or no inclination to eat the food ordered earlier, or infirm limbs where help is essential. Sometimes there is a real antipathy to hospital food which can but only occasional lead to a stand-off. This is where the volunteer feeding buddy has a crucial role to play. This is where experience and time can pay off. Always tell the patient your name and use theirs.

The first positive contribution is someone taking a personal interest in the patient AND having all the time necessary to encourage, urge or seduce the patient into trying a little of the meal. The relaxed 1 to 1 approach pays off more often than not. That someone cares seems to be the central bit of psychology as is the regular appearance of the feeder. The nursing staff appreciate this too.

Some training is advisable. Some hospitals offer this starting with the importance of a warm introduction of feeder to patient. There is a need also to assess the best form of help to be offered. There are a multitude of small

but vital tasks to be judged and carried out. Does the food need cutting up, for the patient to manage themselves? If feeding judge carefully the pace at which the patient can manage...don't hurry! Offer a drink at appropriate intervals. Ask if the patient has had enough and if so wipe their mouth with a moist tissue.....all this is much appreciated. Always ask if there is anything else which is required. Sometimes what has been eaten needs to be recorded.

Sometimes not eating is due to infirmity and sometimes indifference and a judgement needs to be made. As with most things in life personal attention bears fruit. If the patient declares the food to be 'rubbish' always promise to report their sentiment to the cook, but if they declare that it was 'lovely' say you made it especially for them earlier today!

I often say to patients that they will be brimming with energy very soon after the dessert and that the fun run meets at the ward entrance mid-afternoon...... it never ceases to amuse. Though nutrition is the sole purpose of the exercise, raising spirits comes a close second and when combined are important contributors to recovery.

And always smile. It is worth every moment of your time.

Your contribution in this area is sorely needed in most/all hospitals. Do enquire at the Voluntary Services Dept.

David Handley Feeding buddy twice a week at a Yorkshire hospital