The CARPE DEM Model (Care for Every Person with Dementia)
Towards an ideal dementia care pathway?

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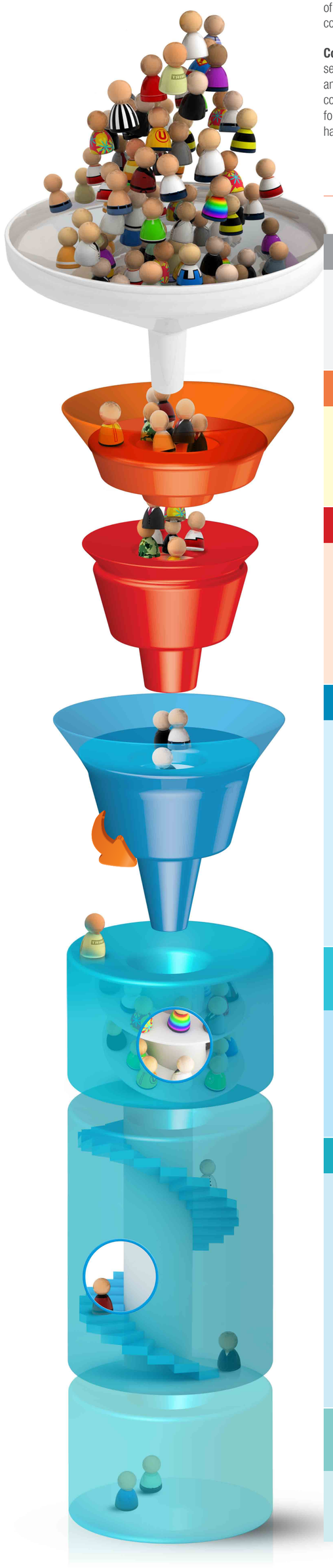
Purpose: to stimulate discussion of dementia care in the United Kingdom



Key components and terminology used in the model

Health and well-being information booth: a display of dementia-related information located visibly in communities.

Community area registration point (CARP): a place/service where members of the public, paid caregivers and health and social care professionals can report any concerns about people who are becoming fragile or forgetful, including those who have been hospitalised or have had falls.

Patient and their carer/support system: the person with dementia and their family member(s) or other primary carer(s); they function as a unit but each have unique needs.

Dementia care coordinator (DCC): a specialist case manager who has dementia experience and stipulated qualifications. A DCC is assigned new cases by the CARP after a diagnosis of dementia has been made. The DCC is the main point of contact for the patient and their carer/support system throughout the illness.

GP: all GPs complete a GP-specific dementia course and are responsible for diagnosing people with non-complex presentations of dementing illness, and for referring other cases to specialists in an Expert Team. They work with DCCs in determining the suitability of care plans.

Visiting nurse: a nurse, attached to a GP practice, who makes a visit every three months (or more frequently) to each person who has been identified as being at risk of dementia because of their fragilities and/or lack of support system.

Expert Team: a team of professionals that is available for use by the GP and the CARP. The team includes professionals in the existing Older Persons Community Mental Health Teams and memory clinics e.g. geriatricians, old age psychiatrists, neurologists, neuropsychologists, and possibly others, such as bereavement counsellors.

Diagnostics: tools or techniques used to identify patients' problems and needs. This model refers to two types of diagnostics: illness diagnostics, which are conducted mostly by GPs, and care diagnostics, which are conducted by a DCC.

N.B. It is acknowledged that there are various conventions in different countries when referring to people with dementia. In this documentation both the terms 'person with dementia' and 'patient' are used. Once people with dementia have been diagnosed, they are referred to as patients to distinguish them from those who have not been diagnosed and to emphasise that they are receiving both medical and psycho-social care interventions.

Recording concerns about people with increasing fragilities at a central location (CARP) to prevent people at risk from being unnoticed or forgotten

- Dementia-related materials are made available from community health and well-being advice booths; details about logging concerns are also provided here
- Falls, fractures and hospitalisations are recorded by GPs
- GPs and dementia care coordinators (DCCs) are educated about dementia, possibly involving three-day dementia education programmes

DECISION POINT

Does the person require regular monitoring?

Those considered 'at risk' receive regular visits and ongoing monitoring for signs of dementia and any related assistance required

- Hospital liaison nurses in hospital-based geriatric teams are linked with dedicated GP practices or visiting nurses
- People at risk of dementia are visited on a three-month basis and assessed for changing needs by specialist visiting nurses connected to GP practices
- New findings are passed to the CARP so that they can be added to previous information and communicated to GPs

DECISION POINT

Does the person 'at risk' require a dementia assessment?

Medical diagnostics: Assess people with signs and symptoms of dementia

- People may go to the GP directly with their concerns about dementia or GPs may invite them to assessment appointments based on information they receive from the CARP
- GPs assess patients for dementia, possibly using new tools, such as the NHG, Observation list for early signs and symptoms of dementia (OLD), triage in dementia (TRIADE), in addition to the mini-mental state evaluation (MMSE)
- GPs refer patients with complex presentations (e.g. those with unusual co-morbidities) for further specialist assessment by members of the Expert Team
- GPs relate information about new diagnoses to the CARP so that dementia care coordinators (DCCs) can be assigned

DECISION POINT

What is the best way to communicate the dementia diagnosis – is a separate appointment necessary?

Level 1 support – starts at time of diagnosis. Formal diagnosis of dementia is given to the patient and their carer/support system. Information provision and support starts now

- GPs communicate the diagnosis/diagnoses sensitively but openly, to the patient and their care/support system, and answer any immediate questions about it
  - Explain and offer any possible anti-dementia drug treatment options
- Patients and their care/support system told they will be assigned a personal DCC who will be an ongoing resource for them, and who can be contacted for any concerns or queries
  - Give address and contact details for the CARP/DCC
  - Give details of local Alzheimer's Café and Alzheimer's Society carer support groups
  - Give information about the national Alzheimer's Society
  - Inform about any current dementia research studies or drug-trial options for possible future participation
  - Provide written information for the patient and carer/support system to take home (e.g. fact sheets with the above details)

DECISION POINT

What immediate care and support does the patient and their carer/support system need?

Level 2 support – follows immediately after diagnosis, with the drawing up and implementation of a personalised care plan for the patient and their carer/support system
Care diagnostics by DCC: assessments and personal care plans done for patient and carer/support system. Care and support are agreed, started, evaluated and adjusted on an ongoing basis

- DCCs assess the patient and their current care provisions
  - DCCs confirm the care needs with patients and their carers/support systems
  - DCCs and GPs draw up care plans, which are agreed and signed by patients and/or their carers/support systems
  - DCCs arrange implementation and monitoring of the care plan, including evaluation of patient/caregiver satisfaction

DECISION POINT

Is the current level of care and support sufficient to meet the needs of the patient and their carer/support system?

Level 3 support – starts when the patient or carer's needs change

- DCCs adjust care plans in response to the changing needs of patients and their carers/support systems
- As dementia progresses, DCCs inform patients and their carers/support systems about services that can provide assistance with:
  - Day care, activities, social outings, support groups, etc
  - Financial and legal matters
  - Planned and emergency respite care
  - Admission to residential and nursing care homes
- DCCs organise services in which patients and their carers/support systems are interested

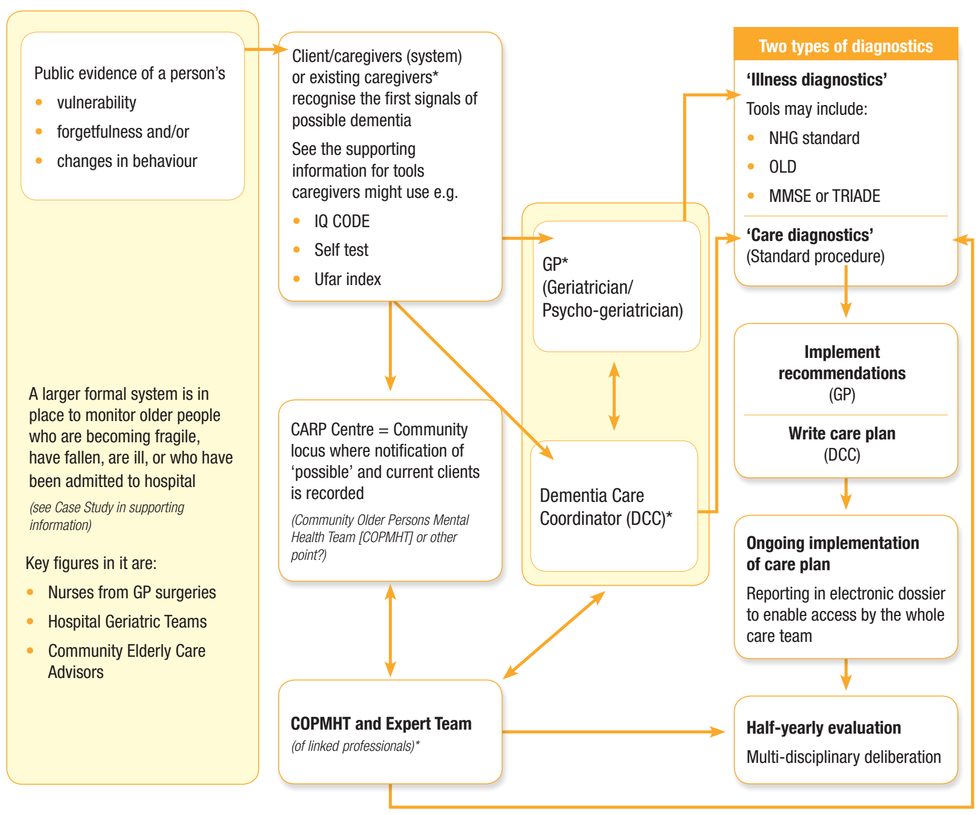
DECISION POINT

Is a move to a care facility required?

Level 4 support (circum-death care) – organised by the DCC for end-stage dementia or palliative care if the patient remains at home (otherwise it is organised by the care facility the patient is in)

- DCCs ensure care is suited to the needs of people in the end stages of dementia and their carers/support systems
- DCCs arrange bereavement counselling if needed

CARPE DEM model dementia care pathway



* Ongoing Education

CARP, Community Area Registration Point; COPMHT, Community Older Persons Mental Health Team; DCC, Dementia Care Coordinator; OLD, Observation List for early signs and symptoms of Dementia; MMSE, Mini-Mental State Evaluation; TRIADE, Triage in Dementia

The Wide Spectrum
dementia education resources

NOVARTIS

"Dementia is clearly a huge concern for all societies and is so common as to be now, and by necessity even more so in the future, a general practice issue. Current concerns about the inadequacy of support for carers, lack of resources for patients and their often inappropriate admissions and readmissions to acute hospitals mean that it is very timely that this new look at the care pathway for dementia care, a version of which has been successfully piloted in Holland, is being discussed. Its focus on general practice and the dementia care manager makes great sense and along with the tools for patients and carers to use to help them understand what is happening, will allow memory clinics to develop as real specialist assessment centres, not the secondary registry and drug treatment monitoring centres they have become."

Dr David Wilkinson (OAP, Founder of MARC, Memory and Assessment Centre, Southampton).

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