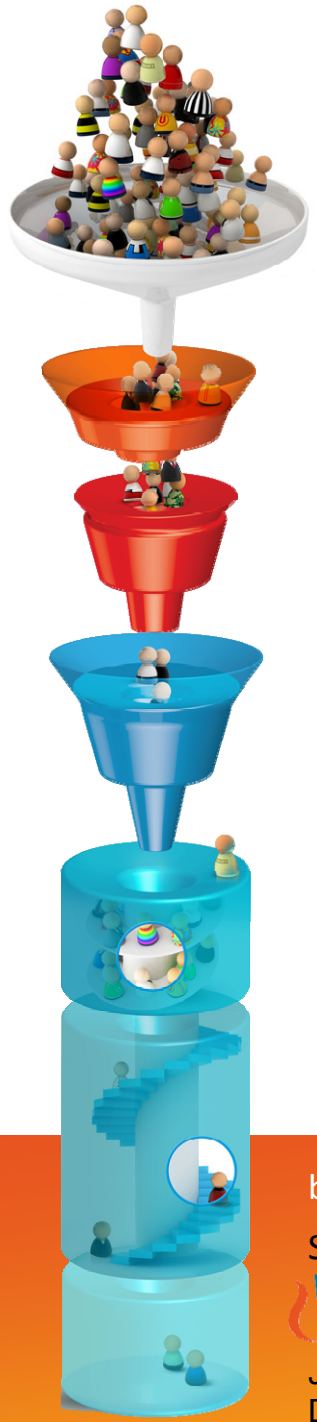

The CARPE DEM Model

(Care for Every Person with Dementia)

Towards an ideal dementia care pathway?

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NOVARTIS

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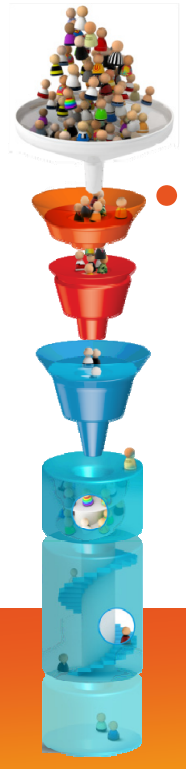
The Wide Spectrum

dementia education resources

Purpose of the toolkit

- This toolkit will provide you with more details to support the information in the CARPE DEM poster
- Please read this toolkit carefully so that you can explain the problems with dementia care in the UK, and potential solutions, to your clients
- Supporting background documentation and references are available separately on the Wide Spectrum website



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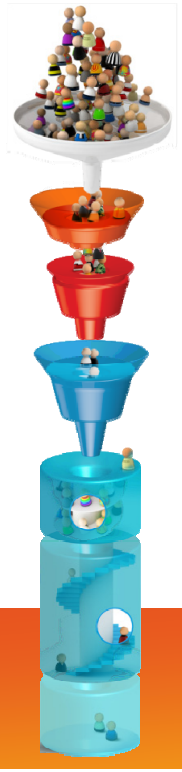
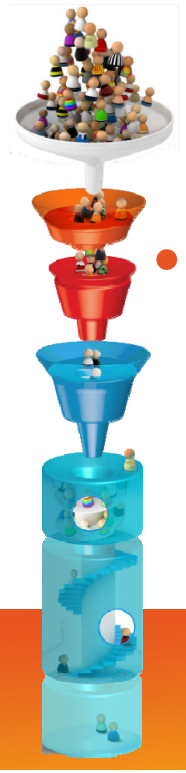
Design of the toolkit

- The toolkit is designed to supplement the CARPE DEM poster, which outlines an ideal dementia care pathway
- Each step in the CARPE DEM pathway is represented by a graphical component, and each page in this toolkit is illustrated with the relevant graphic for the step in the pathway that is described



Towards an ideal care pathway

- Recent research suggests that the prevalence of dementia in the UK population has been underestimated
  - There are estimated to be 822,000 people with dementia (1.3% of the population)[1]
  - 69% of people with dementia are not known to a GP[1]
- A great number of dementia care pathways have been developed. How to identify people who 'fall between the cracks' in diagnostic services remains a key concern



[1] The Alzheimer's Research Trust. *Dementia 2010*

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Who is being missed?

- People who are unknown to GPs include those:
  - Who aren't registered with a GP
  - From ethnic minority groups
  - With limited or no social networks
  - Who are isolated from others, e.g. live alone or in rural communities
  - Who live in sheltered housing or residential and nursing homes
  - Who are displaced and/or marginalised, e.g. prisoners, psychiatric patients, the homeless, people with addictions

Who else?

- Undiagnosed people with dementia may also include those who:
  - Have early onset dementing illnesses
  - Have alcohol-related dementia
  - Have had strokes
  - Are in hospital for acute conditions

The CARPE DEM pathway

- To optimise identifying people with dementia
  - Concerns about all people with increasing fragilities are recorded at a central location (CARP)*
  - Once registered they cannot be forgotten or fall between service cracks

* CARP, community area registry point

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What happens next?

- GPs and Dementia Care Coordinators (DCCs) become the key professionals involved
- GPs and DCCs receive special dementia training
  - A three-day course has been specifically developed for GPs and DCCs. Topics include:
    - Dementia – the illness
    - Assessment of dementia
    - Management of dementia
    - Legal regulations surrounding dementia care
    - Ethical decision making
  - DCCs have post-secondary professional education (minimum)

Those considered ‘at risk’ continue to receive regular visits from visiting nurses attached to GP practices and ongoing monitoring for signs of dementia and any related assistance required

- Early signs that might need investigating include:
  - Making unusual mistakes at work
  - Getting lost in familiar places
  - Forgetting well-known sequences of information, e.g. recipes
  - Driving, shopping, household chores and self-care

Those considered ‘at risk’ continue to receive regular visits from visiting nurses attached to GP practices and ongoing monitoring for signs of dementia and any related assistance required

- Other early signs include difficulties with:
  - Learning new information
  - Handling money
  - Understanding verbal and/or written instructions
  - Remembering current facts, e.g. the name of the Prime Minister
  - Visuo-spatial perception

Medical diagnostics: assess people with signs and/or symptoms of dementia

- Medical diagnostics include:
  - Interviewing the patient and family members
  - Reviewing current medications and recent changes in medication
  - Physical examination (including sensory functioning and neurological tests, if necessary)
  - Noting any recent bereavements or other traumas
  - Noting nutritional and hydration status
  - Testing blood and urine

Medical diagnostics: assess people with signs and/or symptoms of dementia

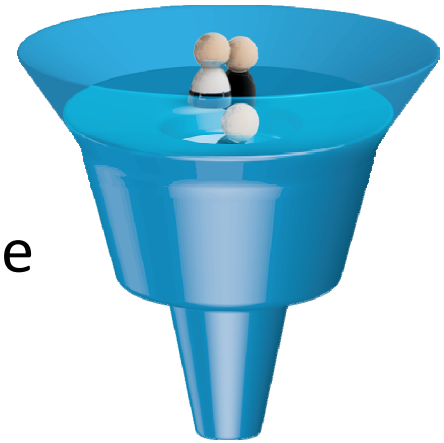
- Medical diagnostics may also include:
  - Activities of daily living (ADL) assessment
  - Mental status tests
  - Cognitive tests
  - Neuropsychological tests
  - Mood assessment
  - Behavioural assessment
  - Brain scans

Medical diagnostics: assess people with signs and/or symptoms of dementia

- Possible tools include:
  - Triage in Dementia (TRIADE), which includes the Mini-Mental State Evaluation (MMSE)
  - Interview for Deterioration in Daily living tasks in Dementia (IDDD)
  - Observation List for early signs and symptoms of Dementia (OLD)
- See supporting documentation for these tools translated from the StIDA project, Amsterdam (2008)

Level 1 support – Formal diagnosis of dementia is given to the person with dementia and their carer/support system

- GPs communicate diagnosis and answer questions
- Drug treatment options that can be discussed with the patient and their carer include:
  - The two anti-dementia drug classes that are currently licensed: **anticholinesterases** and **NMDA-receptor antagonists**
  - Only monotherapy is approved to date; combinations of anticholinesterases with NMDA-receptor antagonists may be licensed in the future
  - Research trials of novel medications
- They are assigned a DCC, who provides a single point of contact for all their dementia needs throughout the course of their illness



DCC, dementia care coordinator

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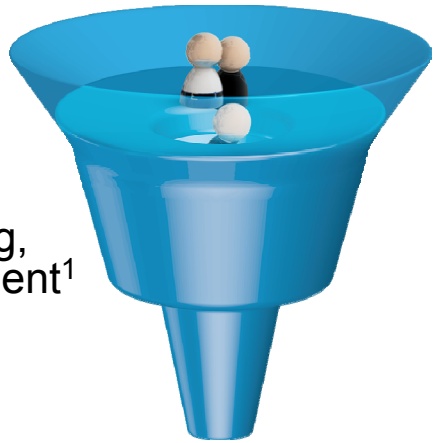
Level 1 support – Formal diagnosis of dementia is given to the person with dementia and their carer/support system

- For optimal drug treatment, the following questions should be considered:
  - What other medications are being taken and what are their side effects?
  - How quickly do you want to reach top therapeutic dose?
  - Is there a need to avoid giving medications that have a bitter taste and the associated loss of appetite?
  - Does the medication cause unwanted visual disturbances?
  - Is the person likely to be compliant with treatment?
  - Is the person new to treatment?
  - Has the person reacted adversely to previous anti-dementia medication?
- Advantages of supporting ADL functioning include delaying nursing home placement
  - Over two years, for every one point decrease in ADL functioning, there is a 3% increase in the likelihood of nursing home placement[1]



[1] Hatoum *et al*. J Med Econ. 2009; 12 (2): 98–103

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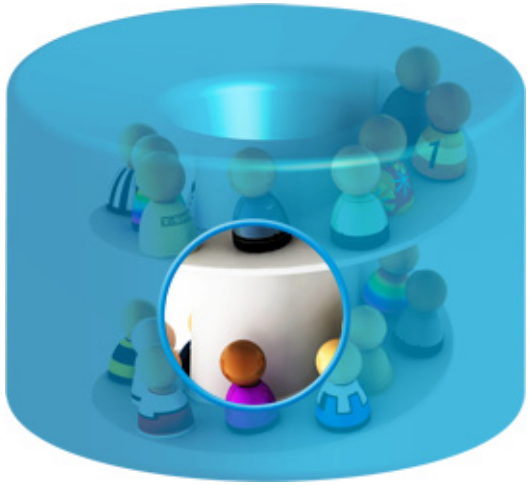
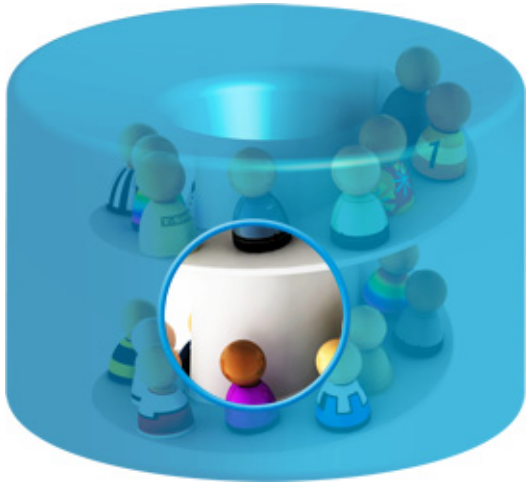
Level 2 support – Care diagnostics by DCC

- **Care diagnostics** includes:
  - Naming the limitations and consequences of having dementia on the person and their carer/support system
  - Assessing their current function, possibly using the PASPC (**P**hysical activity, **A**ctivities of daily living, **S**ocial functioning, carer, **P**sychological/mental functioning, **C**ommunication/perception) model
  - Evaluating effects of comorbidities that may be relevant to care needs
  - Assessing their financial situation



Level 2 support – Care interventions arranged by DCC

- DCCs can arrange the following support and care:
  - Courses for dementia education
  - Discussion/therapy groups
  - Activities/befriending services
  - Legal/financial advice services
  - Domiciliary services
  - Social activities (e.g. Singing for the Brain)
  - Counselling
  - Personal care
  - Transportation
  - Care for physical needs
  - Advice regarding bespoke dementia vacations
  - Planned breaks (day care, respite care)
  - All eventual aspects of dementia care
- DCCs are well positioned to provide information to the patient and their carer
  - Fact sheets
  - Contact details for CARP centre
  - Details of local Alzheimer's Society branch
  - Details of National Alzheimer's Society
  - Local Alzheimer's Café



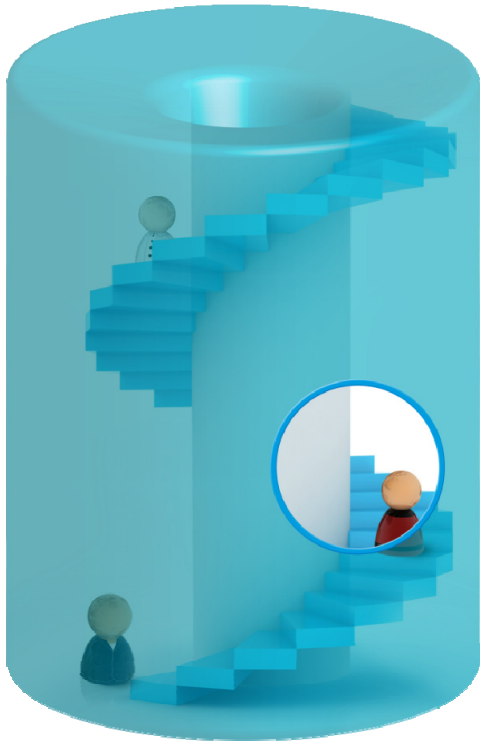
DCC, dementia care coordinator; CARP, community area registry point

Level 2 support – Assessments and personal care plans for patient and carer/support system developed and started

- The care plan is developed according to the patient's particular needs
  - The signature of the patient and their carer/support system is required to show their approval of the care plan
- DCCs are responsible for implementation of the care plan
  - Assessment of professional services
  - Monitoring of service providers' performance
  - Arrangement of six-monthly reviews

Level 3 support – Care and support are evaluated and adjusted on an ongoing basis

- Needs of person and their carer/support system are continually assessed and level of support is increased as disease progresses
- DCCs and GPs review the care plan every six months (or more frequently if necessary) and assess the need for:
  - Day care placement
  - Respite care
  - Temporary admission to care home
  - Permanent placement into care home or nursing home
  - Other standard and local activities that may be of use

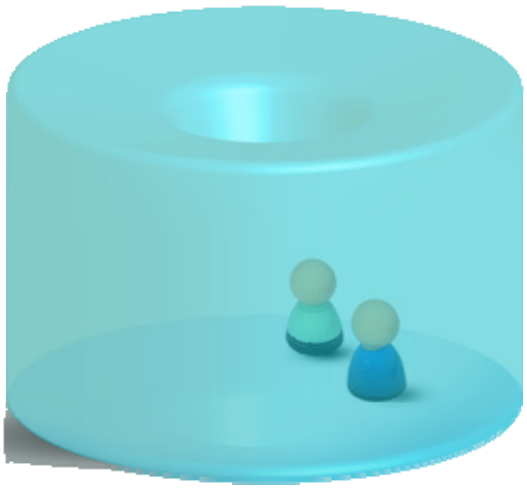


Level 3 support – Care and support are evaluated and adjusted on an ongoing basis

- DCCs also assess the level of subjective satisfaction with the care and support that is being received
- If a person is admitted to a residential or nursing home, the formal inspecting body becomes involved in maintaining standards of care

Level 4 support – Circum-death care

- DCCs and GPs may access palliative care expertise if necessary
  - There is a risk that pain relief needs in particular may not be met in people with dementia



Level 4 support – Circum-death care

- Palliative care includes:
  - Assessment of symptoms
  - Choice of priorities
  - Symptom management (distress, fear/anxiety, pain, dyspnoea, nausea)
  - Sedation
  - End-stage (in bed) sensory stimulation, e.g. music, massage, passive range of motion exercises
  - Creating a stimulating environment, e.g. moving a patient's bed into the living room for a change of scenery
- DCCs arrange bereavement counselling if needed