

## **SUPPORTING PEOPLE WITH DEMENTIA AND THEIR CARERS**

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Malcolm in  
1992, aged 51,  
just after he  
was diagnosed



Malcolm, the day before he died, 2007, aged 66

### **Two thirds of people with dementia are cared for at home (420,000)**

- Organic, progressive, terminal diseases of the brain
- Graham, G and Warner J : *Alzheimer's Disease and other Dementias* (BMA Family Doctor Books)
- Caring for people with dementia is not the same as caring for the elderly frail with their cognition relatively intact.
- Requires special skills, understanding and approaches and access to expert advice on dementia care.
- Staff in a GP Practice are well-placed to pick up tell-tale signs

### Tell-tale signs

- Confusion and forgetfulness are part of normal ageing, but be suspicious when it interferes with everyday living
- Forgetfulness affecting the taking of all medication (Telecare)
- Disorientation: confusing left and right; getting lost
- 84% of people with Alzheimer's have visuo-spatial perceptual problems from the outset and miscue the environment or people's actions. Sometimes is the most significant symptom.
- Mistakes in ingrained skill; losing a recently-acquired skill
- Can't retain new information (e.g. how to work a new washing machine or new medical instructions)
- Repeating questions or the same story a few minutes later
- Problems with tasks requiring sequencing
- Out-of character behaviour.

### Why is early diagnosis important?

- Can be dismissed for incompetence if still of working age
- If suspicious, GP should always refer on to memory clinic or other dementia clinician for accurate diagnosis of the type of dementia and helpful drug (e.g. Aricept)
- Carer should be involved in diagnosis and careplanning (Carer's Strategy). Patient confidentiality vs. best interests?
- New message: you can live well with dementia and there is help and support out there
- Protecting the relationship; uncharacteristic behaviours
- Surgery staff can offer reassurance to seek diagnosis
- Diagnosis is gateway to information and support (Dementia Adviser schemes being piloted). Contact Alzheimer's Society
- Two-thirds of people with symptoms still remain undiagnosed.



## Preserving continence

- 'Accidents'. Is it really incontinence?
- Forgetting where the toilet is, even at home. Keep the door open
- Visuo-spatial perceptual problems; bowl of toilet and flooring in contrasting colours
- Keep clothing simple to pull up and down
- Everyone should have a basic human right to be helped to use the toilet. That also should apply in Day Care settings.
- Inadequate incontinence pads – smallest and cheapest.
- Changing the bed and patient every night in the early hours and mountains of laundry may cause a carer to give up.
- Dignity: pads of the right size, absorbency and of a snug fit.

## Verbal communication

- Many careworkers tend to shout at people with dementia to aid understanding! – a calmer approach is essential.
- People with dementia need time to think before replying
- Don't jump into the awkward silence – wait for a reply
- Simplify your language
- Replying yes (or no) to everything.
- Formal assessments – actively involve the 'significant other' (Carers' Strategy)
- Treating the carer as an expert partner in care
- Carer's oral and written input into e.g. Continuing Healthcare assessments and right to see/check relevant documents – even when the patient is in a carehome.



### Perplexing behaviours/aggression

- Result of recent and mid-term memories being erased, time-travelling backwards and/or visuo-spatial perceptual problems
- Anti-psychotic medication only as a last resort and in the very short term
- Mistaking generations
- “When is mum coming to see me?” Sidestep and latch onto thoughts behind the question. Brutal truth vs protecting feelings.
- Graham Stokes: *And Still the Music Plays* (Hawker 2009) – 22 real-life case studies; key lies in past history – a must-read.
- Pointon: *Eight Caregiving Maxims for Dealing with Perplexing Behaviours* can be copied and handed on.
- Identifying carers; breaks from the 24/7 care – GP funding
- Every carer will be offered an assessment of needs in future.

### Towards enlightened care – a checklist

- It's not what we do, it's the way that we do it that counts.
- No bossiness
- Give people choice (e.g. which of 2 tops to wear today)
- Independence – allow them time to do things their own way
- Preserve dignity (both physical and psychological)
- Don't be tempted to take over – do with, not for people
- Enjoyable, personalised activities
- Fresh air, suitable exercise, varied and nutritious diet.
- Involve willing friends and neighbours – e.g. dogwalkers
- Familiarity of environment; continuity of staff
- Behaviour is an expression of feelings – find the message in it.
- Know when and where to seek expert dementia advice



The dining room, turned into Malcolm's room, with electrically-operated recliner chair, hospital bed, hoist and manual wheelchair

## Tissue viability

- Malcolm never had a pressure sore – wasn't bed-bound; frequent transfers; pressure relief introduced early to prevent problems
- Thorough washing and drying; aloe vera gelly
- Alzheimer's patients resist being rolled on the bed for pad changes (visuo-spatial problems yet again)
- Catheterisation not usually recommended
- Standing hoist the most useful piece of equipment.
- Recliner chair gives support; people with dementia keel over to one side in upright armchairs.
- Positioning is everything in severe dementia



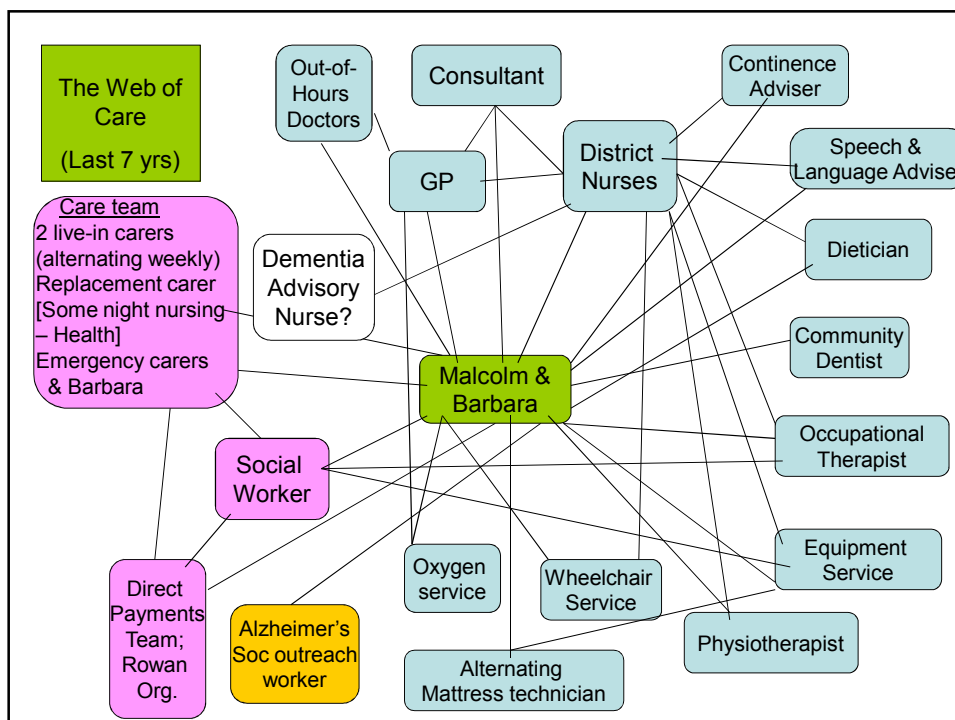
Continuity of staff, plus time and patience are essential.

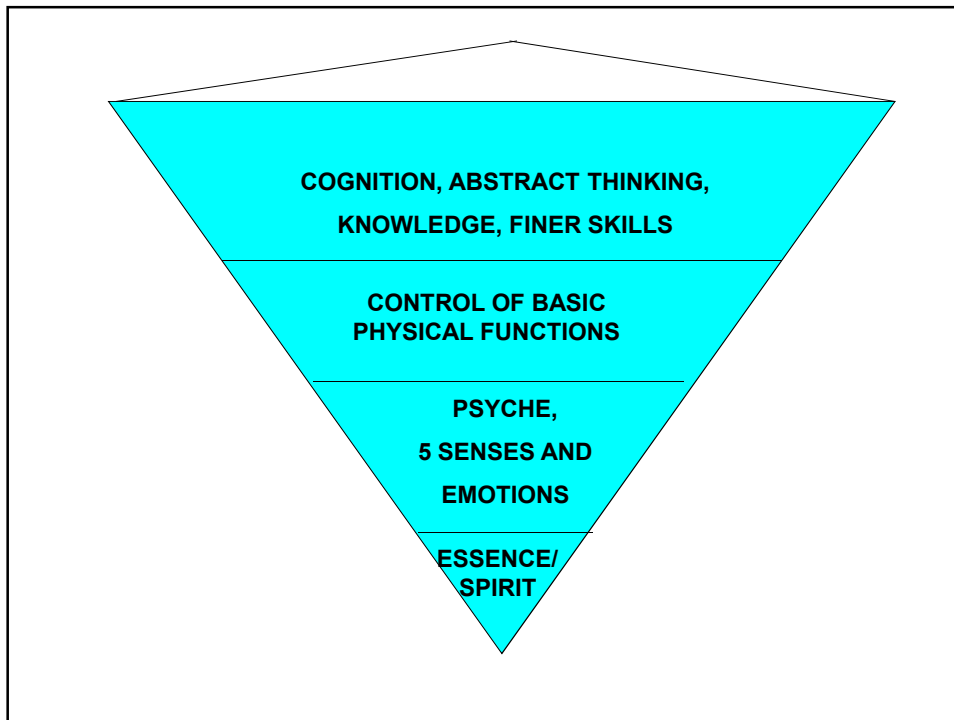
### Swallowing problems: food, drink and elimination

- Took up to 1 hour to offer food to Malcolm by the teaspoonful
- Cold thickened drinks are more easily sensed than tepid ones
- The most trustful thing in the world to open your mouth to be fed – Malcolm would refuse food from a new careworker
- PEG (tube) feeding not recommended in dementia
- Weight loss is inevitable in severe dementia – the brain loses control over the extraction of nutrients from food.
- Constipation: laxatives not the answer; brain no longer understanding signals from the bowel - it's the 'push' that goes
- Keep stool soft; allow bowel to fill up; long time to sit (comfy seat); allow gravity to help; massage; leaning M forward & M pushing back. Black treacle; pureed prunes; 2 bisacodyl suppositories (3 hrs). Final regimen similar to a paraplegic's.

## Medication, analgesia and pain control

- Medication should be reduced in line with severity of dementia.
- Malcolm was on paediatric-sized doses for the last 6 years
- Adult dosage of sodium valproate produced rigidity; clonazepam depressed breathing.
- Mute, unable to point to site of pain; never had pain assessment
- Face became increasingly mask-like – a small frown could mean big trouble
- Oxygen reduced length and severity of tonic-clonic seizures and helped to dry up excess oral secretions
- Specialist nurses tended to see only their bit of the jigsaw and and sometimes gave conflicting advice





### Sensory/emotional/psychological/spiritual needs

- The person is not “a vegetable” and should not be made to feel isolated. TIME needed to stimulate 5 senses:
- Sight: smiley faces; changes of viewpoint; red/yellow spectrum
- Taste: oral feeding; sweeter, stronger flavours;
- Smell: of cooking, aromatherapy; favourite perfume.
- Hearing: favourite music, humming, basic human need to be talked to.
- Touch – the most important. Stroking hands & face; hugs; calming night fears.
- Love is at the centre of all major faiths, but religious or not, we all would want to feel safe and cherished



**Barbara and Malcolm, January 2006**

### **The dying phase**

- With rationality gone, a primitive instinct for survival took over
- Recognising world-weariness and wanting to let go
- Admit to hospital for intravenous treatment or let nature take its course at home?
  
- Unfamiliar, noisy hospital would terrify; earlier evidence: diary
- Not 'starving him to death'
- Died peacefully at home, physically cradled by his close family
- Young grandchildren not excluded – were not fazed by it
  
- Returning to the tip of the pyramid
- Life and death are intertwined

## **Dementia training for all professionals**

Gaining greater understanding about what it's like to have a dementia.

Seeing the patient's needs from the inside looking out rather than from the outside looking in.

Competent, skilful care, generously laced with compassion

What would we want for ourselves and our families in the future?

