WHAT FRAIL OLDER PATIENTS WITH DEMENTIA AND THEIR CARERS WANT FROM PRIMARY CARE SERVICES

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Preface

• 1 in 3 people over 65 will have a dementia in the last year of their life; biggest increase in the very old. Co-morbidities abound

• Half of people over 90 – whose ‘children’ care for them will be themselves elderly and have health issues of their own

• 80% of people living in carehomes have a dementia.

• ‘Carer’= family member or friend taking on the responsibility; ‘Careworker’ or ‘care staff’= paid professionals
The role of the GP in dementia

- Everyone has a GP – elderly people truly value a quality relationship with their GP
- Not the usual forgetfulness; the brain ceases to lay down new memories.
- Patient thinks there is nothing wrong
- Memory tests focus on cognition
- It’s the carer who sees the tell-tale changes in functioning
- Refusing to see the carer independently: “patient confidentiality” can be a hindrance to diagnosis and care.
- Seeing the two together might cause accusations of lying or exaggerating- which undermines their relationship
The carer treated as a partner in care
Supporting the carer

• Through the Care Act, carers gain ‘parity of esteem’
• The person with dementia may not immediately need services but the carer cares from the start
• Giving well-intentioned but the wrong kind of care
• Identification of carer; offer an assessment of needs
• Access to ongoing dementia care expertise for personalised, practical advice and emotional support. One point of contact.
• When carers are well-supported they can provide better care for the person they care for and report better well-being outcomes themselves. (Ablitt et al 2009).
• Two good outcomes for the price of one!
• Averts or delays expensive crises; carer continuing to care longer
What do we want? It’s all in the detail!

• At a surgery consultation, taking away a print-off of instructions for medications and summary of advice given – in a good-sized font, plus a second copy for the carer.
• Better understanding of polypharmacy for the elderly.
• To be treated with dignity and respect.
• Refer on if suspicious – and to diagnose the type of dementia
• A consultation with a dementia specialist in the surgery rather than hospital
• Urge acquiring power of attorney – many leave it too late
• Periodic carers’ health checks (who often neglect themselves)
• Regular breaks from 24/7 vigilance and broken nights
What do we want? It’s all in the detail!

- **Community healthcare staff**
- Electronic records – one person holding the hub for others to access. We’re sick of telling the same story over and over to different professionals
- All assessors of people with dementia and of carers should have expertise in dementia care.
- Incontinence: One size of pad does not fit all! Right size, absorbency and fit. Mountain of laundry every day is the quickest way of causing the carer to give up.
- Community healthcare staff are well-placed to observe whether general domestic help is required.
Too many people - requires one dementia specialist - fewer other, expensive professionals would result
A stony face (the result of losing control of the tiny facial muscles). No response doesn’t mean they have no feelings or thoughts inside.
The Web of Care
(Last 7 yrs)

Care team
2 live-in carers (alternating weekly)
Replacement carer
[Some night nursing – Health]
Emergency carers & Barbara

Malcolm & Barbara

Consultant
District Nurses
GP

Out-of-Hours Doctors/Paramedics
Dementia Advisory Nurse?

Social Worker

Direct Payments Team; Rowan Org.

Alzheimer’s Soc outreach worker

Speech & Language Adviser
Continence Adviser

Dietician
Community Dentist
Occupational Therapist
Equipment Service
Physiotherapist

Wheelchair Service
Oxygen service
Alternating Mattress technician
The dining room, turned into Malcolm’s room, with electrically-operated recliner chair, hospital bed, hoist and manual wheelchair
Education for advanced dementia nursing

• Some usual nursing procedures may need amendment
• Pain control – pain tools designed for dementia (e.g. Disdat)
• All medication dosages should be decreased in line with severity of dementia, regardless of age or weight.
• Neither catheterisation nor PEG feeding are recommended.
• Swallowing: 16 levels of soft food – does the chef know?
• Not the usual constipation – it’s the push that goes
• Patient distressed by respite care away from home – use replacement care at home instead – same person each time.
• Dying phase – avoid admission to hospital – hastens death.
• A peaceful death – supporting the family to care at home