QUALITY OUTCOMES FOR CARERS OF PEOPLE WITH DEMENTIA

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Quality outcomes for carers of people with dementia

- Gaining access to expert dementia care advice; practical and emotional support throughout the journey
- Involvement in care-planning and decision-making, whatever the setting, as a true partner in care
- Having a life of one’s own outside of caring – whole community support and regular breaks
- Support when the caring stops
Relative/friend carers of people with dementia

Research findings:

• 550,000 of us in England.
• Saving a cost to the nation of 7bn a year and rising
• Suffer greater strain and distress than carers of other older people
• Have a unique role: because of the person with dementia’s diminishing cognition, we have to represent and advocate for them
• Mourn a succession of losses
• Intensity of 24/7 care, often over many years, affects our own health and well-being
Key message:

When carers are well-supported, they can provide better care for the person they care for and report better well-being outcomes themselves (Ablitt, Jones & Muers 2009)

2 for the price of 1!
Pre-diagnosis: involving the carer from the outset

• Brain ceases to convert an experience into a memory
• Person believes nothing is wrong with them
• GP refuses to see family member on her own
• Seen together – resulted in undermining of family relationship

• Seeking to give, not receive information; getting at the truth
• Remove this barrier to early diagnosis and support for both.
• A double quality outcome: costs nothing, is deliverable and would boost diagnosis rate.
• Later on – carer requires personal information on a ‘need to know basis’ in order to offer the right kind of care.
Access to expert information and personalised advice

• The new Care Act applies to all adults, including carers. Some clauses apply specifically to carers. A legal First!

• Identification – might become easier
• GP: a duty to ensure that carers’ needs are assessed and a support plan is prepared
• Includes self-funders and carers who are caring or supporting people who are not yet using services
• Will the assessments be just counted, or the outcomes monitored and measured for effectiveness?
Malcolm in 1992, aged 51, just after he was diagnosed.
Access to expert information and personalised advice

• At diagnosis I had no idea what lay ahead. Missed out on good times and forward planning.
• Difficult Conversations (NCPC 2011)
• Made many mistakes in my support and care for Malcolm
• Didn’t need services for 3 years, but offering support began at diagnosis
• Doing my best, but it was the wrong kind of care and it threatened our relationship
• With personalised expert advice, caring suddenly became a lot easier
• Perverse to withhold support until a situation gets critical
• A little money spent early on will prevent more expensive crises further down the line. Role of dementia charities.
Continuing tailored advice and emotional support through all phases of the illness.

- Learning to find reasons behind perplexing behaviours
- Making allowances and stop thinking that he or she is ‘being deliberately awkward’ or ‘doing it to spite me’.
- Protecting the relationship
- Emotional support from another human being is priceless
- *Dementia – Support for Families and friends* (Pulsford & Thompson; Jessica Kingsley publ. 2013)
- *And Still the Music Plays* (Graham Stokes; Hawker publ. 2008)
- Dealing with a litany of losses: continence, speech, mobility, swallowing problems
- Normal nursing procedures needed to be amended
John (careworker) with Malcolm – patiently hand-feeding
Out-of-Hours doctors & paramedics
District Nurses
Consultant
Malcolm & Barbara
Dementia Advisory Nurse?
Malcolm & Barbara
Social Worker
Alternating Mattress technician
Oxygen service
Wheelchair Service
Dietician
Speech & Language Adviser
Continence Adviser
Occupational Therapist
Equipment Service
Physiotherapist
Community Dentist
Care team
2 live-in carers (alternating weekly)
Replacement carer
[Some night nursing – Health]
Emergency carers & Barbara
Direct Payments Team; Rowan Org.
Alzheimer’s Soc outreach worker
Care team
The Web of Care (Last 7 yrs)
The advantage of a single source of expert advice – a trained dementia nurse

- Simplification and integration more possible
- Sees the whole picture
- Holds one holistic record electronically for others to draw on
- Gets to know the patient and family well – a triangle of trust
- Able to counsel and console the carer
- Top of every carer’s wish-list is a single point of contact
- Working with several GP surgeries in an area and be a source of advice for home care, hospital ward staff and carehomes
- Dementia is as serious as many other conditions which already have a practice nurse.
Carers treated by professionals as partners in care

- A two-way traffic
- Carer’s knowledge about the person’s needs fed into all assessments, hospital discharge and care plans; involvement.
- They have a right to be involved in discussions with professionals in Continuing Healthcare assessments
- ‘Respect and dignity’ – valid for person with dementia and their carer – “parity of esteem” (Care Act)
- Trust in carers: “is a key part of any caring partnership and without such trust it is highly unlikely that the person with dementia be given the best possible support”. (Nuffield Council on Bioethics 2009)
Partners in care in a carehome

- Carers still care about their relative or friend
- When poor care is offered, should we make waves or stay silent? Fear of repercussions on the resident?
- An example of overmedication for the benefit of the staff.
- Loss of quality of life
- Advocating for someone who could not speak up for himself
- Both Malcolm and I had a better sense of well-being afterwards. Another 2 for 1 quality outcome!
- Cultivating partners in care in all carehomes and hospitals?
Nana’s come to play! The grandchildren show me the chalk pictures they have drawn
A life of my own outside caring – community support and regular breaks

- Relief from the eternal vigilance
- Support from neighbours
- Support from the local Primary school
- Quality outcomes costing nothing but time and goodwill
- The emergence of dementia-friendly communities and Dementia Friends
- Planned breaks
- Downside: Malcolm came back in a worse condition
- No memory of being there before – feeling abandoned
- Replacement care at home – same person every time
- Carers won’t take breaks unless the replacement care is good
When the caring stops

- It stopped twice. Felt most bereaved with Malcolm in a carehome
- Death - relief and release – declined bereavement counselling
- Delayed shock (physical and mental) hit me 16 months later – one month’s delay for each year of caring
- GP unaware of cause – who’s radar should we be on?

- Former carers – empty hands - voluntary work around dementia – forming a useful workforce.
- BUT – yards of red tape wrapped around volunteering these days - which is off-putting to carers. Any hope of slackening?
- Less carer support now than when I was caring.
The Dementia Action Alliance: Carers’ Call to Action

- **Five goals to be achieved by 2015:**
- **Carers..........**
- 1. Are recognised as essential partners in care, because of the particular nature of dementia and the impact of cognitive deterioration
- 2. Have access to expertise in dementia care for personalised information, advice, support and co-ordination of care
- 3. Have confidence that their own needs and requirements are recognised and supported, so that no carer feels alone, and are give regular breaks to avoid carer breakdown
The Dementia Action Alliance: 5 Goals

• 4. Carer’s assessments should identify the ongoing and changing support needs of the carer to maintain their health and well-being, thereby valuing the support carers provide to enable the person with dementia to live well.

• 5. Access to good quality care and support services, including respite, that are flexible, appropriate, timely and provided by skilled staff for both themselves and the person they care for.

• 20-point checklist for commissioners and new booklet for carers to stimulate growth in carer support in their locality.

More info from www.dementiaaction.org.uk/carers
or email admin@carersdementioaaction.co.uk

Please help us, in any way you can, to achieve these goals