Dementia care - working together to support complex needs

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Dementia
- ‘everyone’s business’

- **850,000** people in the UK with dementia
- **40,000** people under 65

- **63.5%** in community
- **36.5%** in care homes (approx. 69% with dementia)
- **25%** of people in hospital

Complexities in dementia

- **Pre-diagnosis**
  - Recognising changes
  - Co-morbidities
  - Reducing risk factors

- **Diagnosis**
  - Fear / stigma
  - Co-morbidities
  - Different symptoms / types

- **Living with dementia**
  - Changes in function, behaviour & capacity
  - Impact on family/friends

- **End of life & after death**
  - Poor recognition
  - Best interest decisions
  - Access to palliative care

**Dementia UK**
Improving quality of life
Co-morbidities and dementia

- Only 17% people with dementia just have dementia
  Scottish School of Primary Care (2012)
- 41% Hypertension
- 32% Depression
- 21% Chronic heart disease
- 19% Painful condition
- 18% Stroke/ TIA
- 13% Diabetes

- Other common problems:
- Undernutrition and weight loss, urinary incontinence, urinary tract infection, hearing and visual impairment, pain, falls
Family Carers

- An estimated **21 million people** know a close friend or family member with dementia – 42% of population
- Approx **550,000** carers of people with dementia in England.
- Carers save economy approx **£7 billion** per year
- Rates of depression and anxiety are **high**

**Critical points in caring**

- At diagnosis
- Taking on active caring role
- When capacity declines
- Need for emotional support
- Person's mobility declines
- Person has other health problems or behaviour problems
- Person becomes incontinent
- Carers circumstances change
- Decisions about residential care and end of life care

*Carers Trust (2013) A Road Less Rocky – Supporting carers of people with dementia*

*Alzheimer’s Society (2014) Dementia; Opportunity for Change*
Supporting people at pre-diagnosis

Promoting awareness
Sharing information
Encouraging assessment
Regular health checks
Identify risk factors
Carer engagement
VIPS framework

- Valuing
- Individuals
- Perspective
- Social environment

From Kitwood (1997)
Dementia Reconsidered

Brooker (2006)
Supporting people at diagnosis

- Person-centred assessment
- Carers assessment
- Planning for future
- Specialist support

Agreed assessment tools
Skilled knowledgeable practitioners
Supporting people to live with dementia

• Managing complex conditions
• Pharmacological treatment
• Psychosocial interventions e.g. life story, music, activity, CST,
• Social engagement/ peer support
• Carer support - balancing needs

‘I am living with dementia ....not dying with dementia’.
Supporting people at end of life

- Pain management
- Individualised care plan/ PPC
- Best Interests decisions
- Palliative support
- Carer support
Complexity within a complex system!
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

Dementia care coordinator / specialist nurse

Out-of-Hours Doctors/Paramedics

Consultant geriatrician

District Nurses

Continence Adviser

Speech & Language Adviser

Dietician

Community Dentist

Occupational Therapist

Equipment Service

Physiotherapist

Oxygen Service

Wheelchair Service

Alternating Mattress technician

Alzheimer’s Soc outreach worker

Direct Payments Team; Rowan Org.

Social Worker

Courtesy of Barbara Pointon
The National Dementia Strategy has resulted in a change in attitudes **BUT** commissioning of local services to give people with dementia and their families quality of care and quality of life has a long way to go.
So what next?
Person with dementia

NOT

Person with dementia

Kitwood (1997) Dementia reconsidered
Working in partnership

People living with dementia

Practitioners

Family carers/friends
Prime Minister’s challenge on dementia 2020

- Risk management & reduction
- Support after diagnosis
- Supporting carers: Care Act 2014, NHS England Commitment to carers
- Care at home- Better Care Fund
- Care in hospitals & care homes- Dementia Friendly Charter
- Reducing antipsychotic medication
- Increasing dementia awareness & education
  - Care certificate, HEE Knowledge & Skills, Social workers
- Research
The House of Care- Enhancing the quality of care for people living with long term conditions (NHS England)
Supporting people along the pathway

Pre-diagnosis

Diagnosis

Living with dementia

End of life & after death

Continuity, co-ordination & collaboration

Dementia specialist services /hub: memory service, social care, dementia advisors, dementia specialist co-ordinators/nurses

GP Health check

Social worker care assessment

Home care, & community services

Hospitals, care homes, hospice

Commissioning of high quality, Integrated services
Admiral Nursing

- Qualified specialist dementia nurses
- Support family carers and people living with dementia throughout the dementia journey, particularly during complex periods of transition
- Provide education, leadership, development and support to other colleagues and service providers
- Improved support for carers & people with dementia, reduced admission to hospital and save money!
The key to success?

- Learn from what works
- Access further education/ training
- Share information & good practice
- Work together!