Frank Arrojo
Former carer
Member of the new “Involvement network for family carers of people with dementia”
The Carers’ Call to Action

Supporting the needs and rights for family carers of people living with dementia
The New Carers Involvement Network for carers of people with dementia

Listening to the Experts

Leading change in dementia diagnosis and support
Kings Fund
24th February 2015

Jean Tottie
Chair
Life Story Network
www.lifestorynetwork.org.uk

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Who we are – our story....

We are a community interest company made up of a network of individuals and organisations dedicated to sharing knowledge and promoting the value of using narrative approaches, including life stories to improve the quality of life and wellbeing of individuals and keeping them connected in their local communities.
So what is narrative practice?

“Narrative practices place emphasis on stories and conversations in contrast to relying on pathology to tell us about clients” (Stewart 2011).

- Using narrative approaches celebrates a persons’ individuality, their experiences, their culture, their passions, and their interests and is a foundational basis for establishing a relationship with the person that begins with respect.

- Narrative practice and approaches
  - Centres on people as the experts in their own lives.
  - Enables us to view the problem as separate from the person
  - works from a strengths basis, believing that people have many skills, competencies, beliefs, values, commitments and abilities that will assist them to reduce the influence of problems in their lives.
‘A diagnosis of dementia is given not just to one person – it is given to a spouse, a partner, a child and the extended family’

Providing timely support, information and respite can make the difference between swimming and drowning

Alistair Burns
Our work with family carers

• Piloted in 2012 as part of our initial ‘Your Story Matters’ DH funded work, co designed and co-produced with family carers
• Refined it working with family carers in Tyne & Wear
• Have now run a number ‘Family Carers Matter’ programmes with family carers
  – Tyne & Wear
  – Rochdale
  – Halton Borough Council
  – Liverpool
  – Mersey Care NHS Trust
  – Greater Manchester NHS Foundation Trust (Bolton, Salford & Trafford)
  – Hartlepool Carers Centre – moving on to an embedded model
Why do carers matter? – The evidence

• 800,000 people living with dementia and the majority living in the community being cared for by a family member or friend;
• 670,000 unpaid carers of people with dementia, saving the UK economy an estimated £11.6 billion (44% of the total cost of dementia care);
• Carers reported they received insufficient support from health and social care services, leaving them feeling isolated, burnt out and unable to look after their own health (Carers UK);
• Two thirds have reported suffering from depression as a result of their caring role;
• Carers of people with dementia experience greater strain and stress than carers of other older people;
• Almost 50% of the carers of people with young onset dementia were either not getting or only sometimes getting support in their caring role.
Cost of not supporting carers - the consequences

• Additional costs to NHS – carers ill health;
• A more intensive care package required for the person living with dementia either at home or a placement in residential care;
• From a business perspective (The Centre for Economics and Business Research (CEBR) (2014):
  – 12.1% carers, who are employed have to reduce their working hours to accommodate their caring role;
  – 9% have had to give up work to prioritise their caring responsibilities;
  – 1’n 5 businesses have had members of staff leave to take care of a relative with dementia;
• Loss of skills and experience from the workforce in business costs £1.2 billion in 2014;
• In 2014 alone, 50,000 carers had to quit their job and a further 66,000 had to make adjustments at work;
Supporting carers – what has happened so far!

- National Dementia Strategy
- Uniting Carers - Dementia UK
- Prime Minister’s Challenge on Dementia
- Dementia Action Alliance - Carers Call to Action
- Triangle of Care
- The All Party Parliamentary Group (APPG) on Dementia
- The New Care Act - A principle of ‘well-being’ in the Care Act 2014 refers to those with care needs and those who care for them.
- NHS Commitment to Carers – launched in Dec 2014
- New Vision for Dementia (in draft)
The New Carers Involvement Network

“I am also pleased to announce today that the Department of Health will be providing funding to develop an ongoing network to support the needs and rights of family carers of people with dementia. I wish you well in this important work.”

Statement of support from Norman Lamb MP, Minister of State for Care Services

“I'm pleased to announce today that, with the help of the Department of Health with some start-up funds, a new involvement network of family carers is to be formed to build on the good work of the Carers Call 2 Action and which will ensure the voices of family carers are heard. The network will be hosted by the Life Story Network which is doing a lot of work with family carers”.

Prof. Alistair Burns, National Clinical Director for Dementia in England
The New Carers Involvement Network

Aim of the network will be to:
Work with family carers of people living with dementia so they can continue to care and support the person they are caring for, for longer by developing their confidence, capabilities, capacity and resilience and by achieving this can share their caring experience with others.

Objectives
• Engage carers to raise the profile of the needs of people with dementia and family carers and influence policy
• Equip carers with the knowledge and skills to advocate for improvements in standards and better services
• Encourage & enable, family carers to become involved and campaign for improved services and standards of care
• Empower carers by developing confidence in their capacity to support each other and to make a difference in their community
• Evidence the value of enabling family carers to participate and share their experience which contributes to their own health and wellbeing

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The New Carers Involvement Network

The outcomes of the network for family carers

• Improved health and wellbeing by remaining connected and supported with the caring community and their peer groups
• Feeling valued as they are recognised as experts by experience
• Increased knowledge, understanding and confidence leading to more control over their lives
• Able to care better and for longer
• Skills developed that will enable carers to re-enter the workplace

The impact on people living with dementia being cared for

• Maintain a positive relationship with their carer
• Remain living independently for longer
• Stay connected with their community and support structures
• Supported to share their experiences
The New Carers Involvement Network

Benefits to stakeholders

- Access to diverse groups of trained & supported carers via a central and coordinated resource:
- Speak on training & education programmes
- Speak at conferences & workshops nationally, regionally & locally
- Campaign for better services to CCGs, H&WBs, politicians
- Participate in evidence gathering for specific reports through surveys and focus groups
- Participate in research programmes (essential PPI)
- Represent the voice of carers to media locally, regionally and nationally

Benefits to the wider community

- Reduction in acute care costs
- Reduction in long term care costs
- Reduced crises
- Reduced hospital admissions
- Potential reduced need for medication
- Transfer of carer’s knowledge and skills to others living in the community in a similar a caring role
- Enhancing employability skills to re-enter the workplace
- Reducing social isolation through the creation of specialised support peer groups

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Thank You!
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