

The State of Caring – A personal perspective on 21st Century challenges and opportunities

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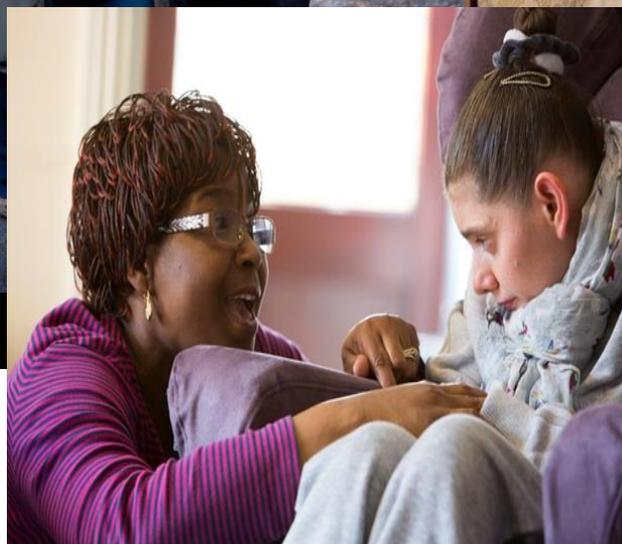
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A culture change in 'thinking carer' – from institutions to community but challenges along the way! Is the Care Act 2014 making a difference?



WHO cares? Understanding carers: Opportunities and challenges for the Government in meeting the needs and *aspirations* of a changing population of carers.



Who cares? Demographic change means carers are everybody's business!

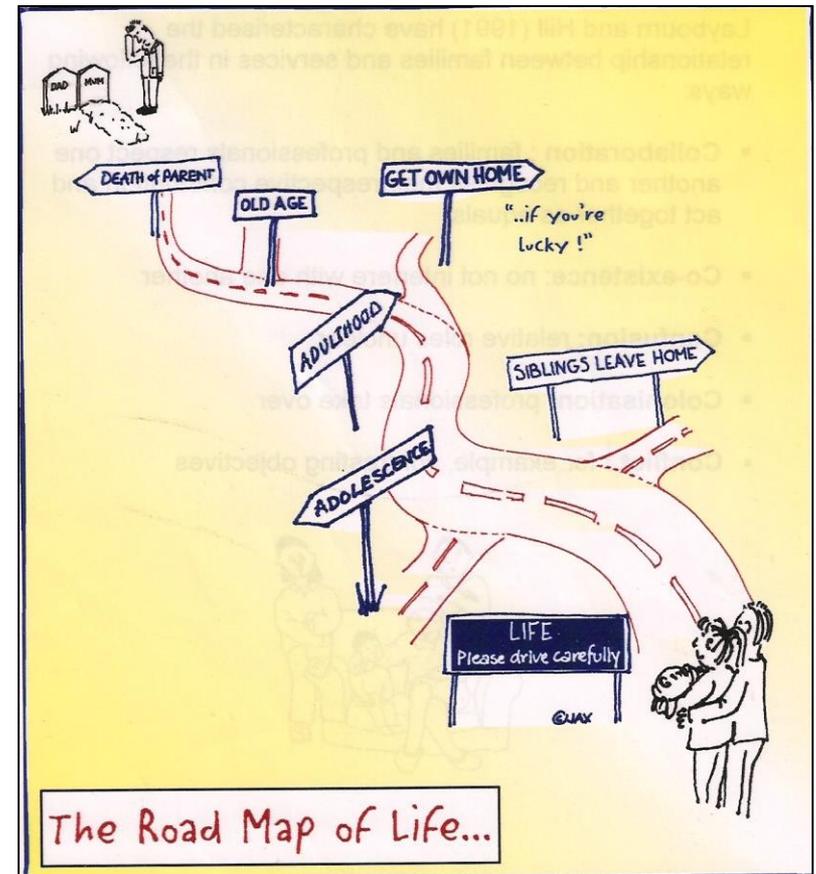
- **6.5 million carers in UK** and number of people over 65 with care needs projected to grow from 2.5 million in 2010 to 4.1 million in 2030.
- **33% of older people have at least one long-term condition**, with numbers of people with three or more conditions likely to double by 2018.
- **8 in 10 carers have felt lonely or socially isolated because of their caring responsibilities.** 78% have significant depression or anxiety levels.
- **'New survivors'** – numbers of adults 18-64 with learning disabilities expected to rise by 32% over the next 15 years.

WHO cares? We need to improve patient AND carer experience for the best outcomes. [Kings Fund, 2015]

- *Even people with long term conditions who tend to be heavy users of the health service are likely to spend less than 1% of their time in contact with health professionals. The rest of the time they, their carers and families manage on their own....we need to recognise that patients, their families and carers are 'experts by experience.the NHS will increasingly need to dissolve traditional boundaries. Therefore the NHS needs to manage systems, networks of care, not just organisations – and recognise family carers as key partners in recovery.'*

‘21st century is caring from the cradle to the grave - you need a satnav for caring now, it’s long term, the road is windy and you acquire fellow travellers along the way!’

- Will the Care Act work? We need ‘whole family approaches’ for 21st century caring.
- ‘Caring is about managing multiple transitions, some good, some bad’.
- ‘Caring shouldn’t be a dead end – we can ALL have a good life if we are listened to as active partners in care’.



Making the transition – new opportunities and expectations around moves to adult life.

- Children and Families Act 2014 sits alongside the Care Act 2014.
- Legislation gives transition a ‘new status’.
- A strong focus on skills for living and maximum independence within the Education, Health and Care Plan.
- Ambitious about outcomes (whether for education, training or employment).



Young carers – *'I started caring when I was five years and it has continued all my life ever since.'*

- 166,363 young carers in England
(280,364 young adult carers 18-14)
- 15,000 children provide 50 hours a week or more of care.
- High risk of education or health problems.
- Caring often escalates for young adult carers, with major implications for education, training and employment.



‘Keeping going’ - The rise (and fall!) of the ‘squeezed middle’- the ‘sandwich’ carer!

- Welcome recognition of the rise of the ‘working’ carer in the Care Act and forthcoming new Carers Strategy.
- But over 315,000 working age carers have left work and remained out of employment.
- Welfare reform – Carers Allowance and ongoing debate about benefit caps for family carers..



Caring in later life – *‘a strenuous life, an unfinished journey, no cruises into the sunshine for me!’*

- A reminder about changing families: 1.2 million carers aged 65 and over in England.
- 60% of older carers providing 50 hours or more care a week say their own health is not good.
- Decrease of 9% in offer of carers’ assessments to carers aged 75 years or over.



The big ambition ‘ageing well’, but listening to the carers’ dilemmas

- Nearly half of carers aged 85 or over are caring for someone with dementia
- ‘The ‘big curse’? I can reassure you that however it may feel at the beginning, it is still possible to live a life of quality with dementia. Not the life you had before, perhaps, but a life full of promise all the same – **Hear us, support us to live not just survive!**’ [James McKillock].



A new direction: Personal Budgets and Direct Payments – Making a difference and redefining ‘social care and support’ [TLAP/POET Survey, 2014]

- **Carers of all ages report positive outcomes** (better quality of life; improvements in physical health and well-being).
- **BUT we need to develop key role for carers in local market shaping** (eg building community capacity, micro enterprises, pooled personal budgets) – what do WE want?
- **A spirit of co-production -** New partnerships with health and housing and third sector .



A carer friendly NHS? A welcome commitment to carers across the NHS but a challenge to make recognition and integration a reality!



Creating carer friendly communities: Ask the carers? [Simon Stevens (CEO, NHS England) talks to carers at a Summit at London Zoo]

- **‘Culture change** – encourage carers of all ages to ‘co-produce’ local care and support services.
- **Recognition** of the importance of OUR health and well-being!
- **Personalised care and support and a life alongside caring** – we’re ‘experts by experience’ – if you ask us!



Reminders from London Zoo! – what do 21st century carers want? *‘Actually our big ambition is quite small, we just want an ‘ordinary life’, a support system not a service!’*

- **Relationships, respect and early identification** – *‘Low level support, information and advice make a difference – recognition matters!’*
- **Whole family approaches** – *‘talking about real lives, not eligibility!’*
- **Services and support which are high quality, safe and achieve the best outcomes for everyone in the family.**
- **Integration!** Making sense of multiple sources of health and support, with accessible information, record keeping and care plans.

An opportunity and coming soon – a new National Carers Strategy !

- Will run 2016-2020 (and will be Cross-Government (led by DH))
- Will cover ‘full life-course of caring’, including young and ‘sandwich’ carers.
- Key themes likely to be:
 - **Identification, recognition and early intervention**
 - **Financial and economic impact of caring**
 - **Physical and mental health and well-being and a life alongside caring.**

Developing the National Carers Strategy - what next?

- **An Economic Review** (including carer income, ie tax and benefit systems) and economic impact of caring on carers and society more widely)
- **An International Review:** What can we learn from other nations' experiences.
- **A UK Review** of national practice and a call for evidence [YOUR opportunity coming soon to contribute to the debate.]

The Care Act one year on – co-producing better outcomes for carers!

- The Carers' Trust has set up a Commission to gather evidence on carers' experiences about how the Care Act is working one year on.
- A real opportunity to say what is happening in your area and what YOU want?
- E-mail careact@carers.org or go to the website at: www.carers.org for more information
- The Care Act is a 'once in a generation' chance to improve lives for carers. Caring is often described as a 'juggling act'. In hard economic times, our views matter more than ever – please share them!



And a final postscript that caring is much more than a 'costed' service. It is about real lives and relationships for real people!

Maya Angelou

I've learned that
people will forget what you said,
people will forget what you did,
but people will never forget
how you made them feel.

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