

Who cares? – A personal perspective on the changing roles of UK carers in private and in public life.

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A personal journey and a culture change in 'thinking carer' – from institutions to community [a 'quiet revolution' in recognising and valuing carers]



21st Century Carers – a reminder about the ‘backbone of the UK health and social care system’

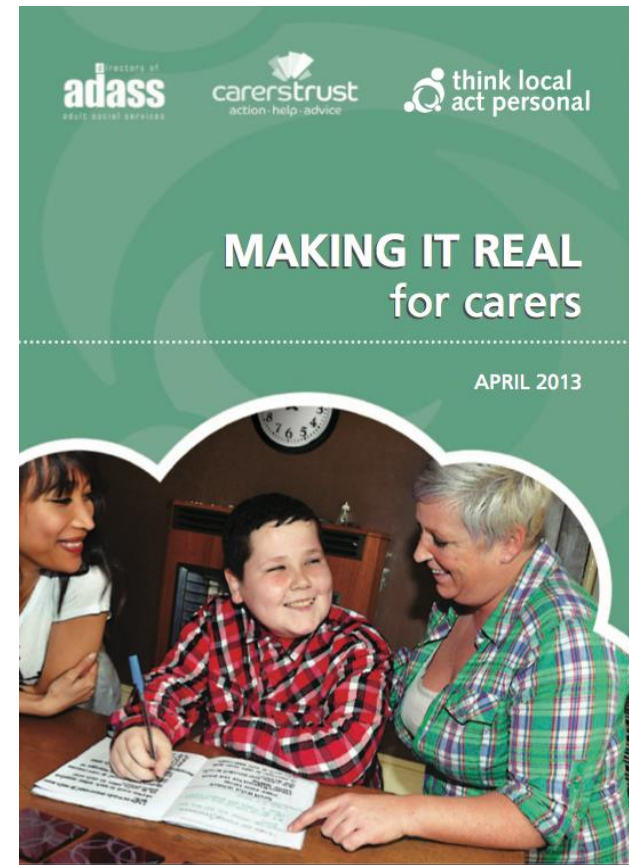
- **6.4 million carers (500,000 dementia carers)** – numbers expected to reach 9 million by 2037.
- **54% of carers give up work to care** – major financial implications for many families, with carers emphasising that the best support for everyone would be quality care for their relative.
- **166,363 young carers in England** (280,364 young adult carers 18-14)
- **‘New survivors’** – Numbers of people with learning disability aged 45 or over expected to increase by 32% over coming decade.
- **75% of carers report significant depression or anxiety levels**, with similar numbers reporting range of health problems ‘related to caring’.

‘Carers at the heart of 21st century families and communities’: The Standing Commission on Carers and a new agenda for care and support in England.

- **Created 2007** by previous Prime Minister to ‘rethink policy on a changing population of carers and produce a ten year strategy to both design and to embed change.’
- **Key role to provide independent expert advice and act as an ‘observatory’ for Government Ministers and Government Departments.**
- **Independent but within Government:** Bringing together key stakeholders from Local and Central government; health and social care; professional organisations and most importantly carers themselves and the independent carers’ sector!

How the Standing Commission on Carers works – a strategic partner in change

- **Reconfiguring social care and support** – meeting the challenges and opportunities of a changing population of carers and high expectations of personalised support at home and in local communities.
- **‘Co-production’** across the NHS, Local and Central Government, professional bodies, third sector – and carers themselves!
- **‘Care matters!’: Building an evidence base for carer support.**



A changing landscape: The carers' journey in the UK – changing expectations from 1960s onwards

- Rejection of institutions and new emphasis on family carers (and on the rights of disabled people as citizens)..
- The emergence of strong carer advocates – Carers UK, MENCAP and others.
- Carers assert their own independence not only as primary care givers but as ‘partners in policy-making’.

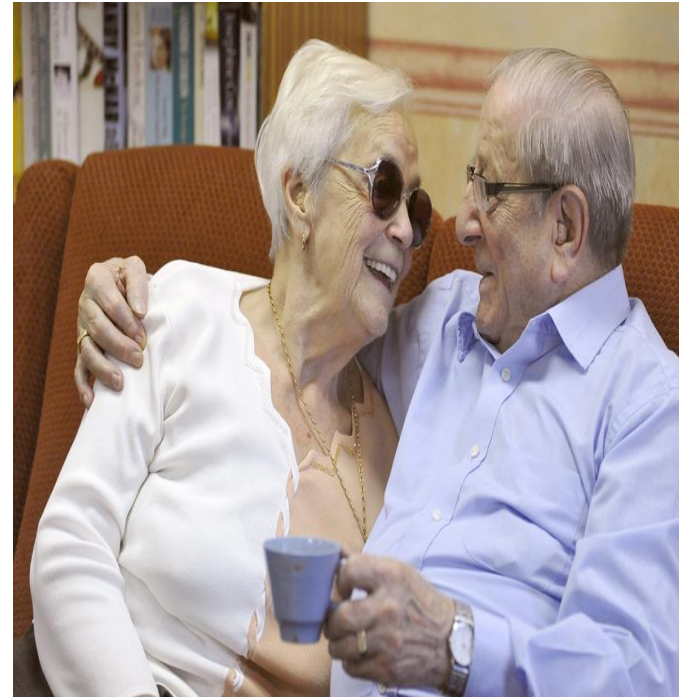


‘Keeping going’ – Employment a key issue for the rise (and fall!) of the ‘squeezed middle’- the ‘sandwich’ carer!

- Welcome recognition of the rise of the ‘working’ carer in the Care Act 2014 and Second National Action Plan.
- But over 315,000 working age carers have left work and remained out of employment.
- Employment for carers key issue for Standing Commission: recognising the rise of the ‘sandwich carer’ and the 21st Century multi-generational family.
- ‘*Getting a life*’ – 1.2 million carers spend more than 50 hours a week caring – a workforce larger than the NHS in England!
- Carers UK/ Standing Commission on Carers – understanding the *economic as well as social arguments* for enabling carers to carry on working (or, for young adult carers, to enjoy the career opportunities open to their peers.)

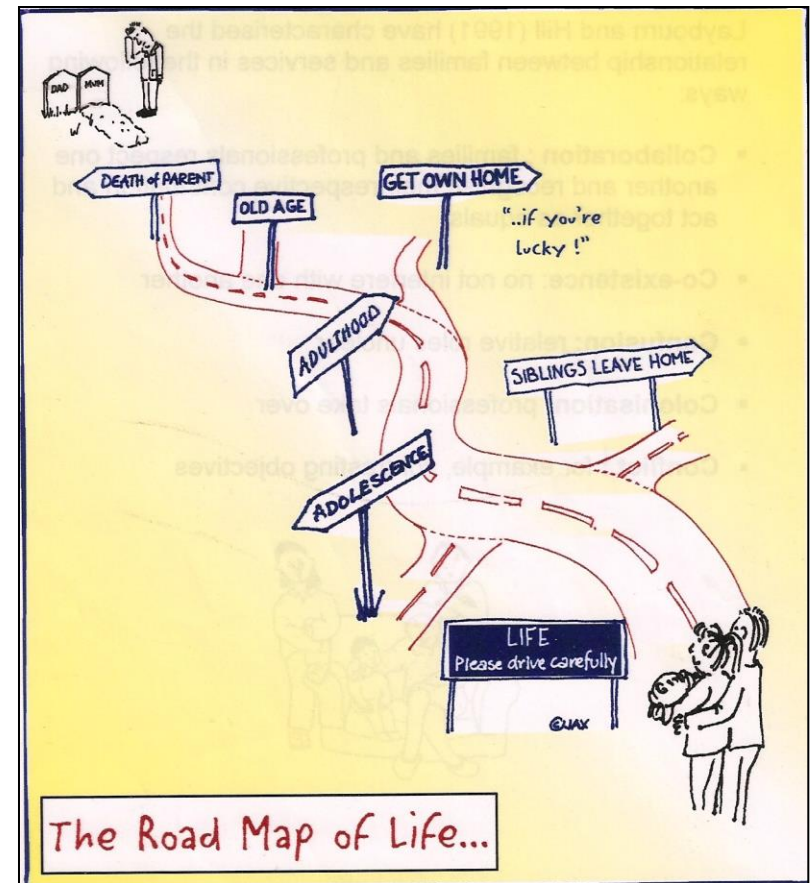
The big ambition ‘ageing well’, but ‘the age of no retirement’

- 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 and Marion McKillock].



Changing attitudes to caring: '21st century caring can mean caring from the cradle to the grave – Caring is about managing multiple transitions!' [family carer]

- **The big ambition:** We need 'whole family approaches' for 21st century caring.
- **'Caring for the carers** – we need to find better ways of protecting the health and well-being of carers themselves.'
- **'Caring shouldn't be a dead end** – we can ALL have a good life if we are listened to as active partners in care'.



The Care Act 2014 and NHSE Commitment to carers – ‘Blue sky thinking’ with carers in the ascendant – as active partners in a changing landscape for care and support.

- **The Care Act 2014 and NHS England’s Commitment to Carers** – unique opportunity to integrate social care with health, housing and education!
- **Personalisation and partnership** – co-producing new patterns of care and support *with carers*.
- **21st Century carers** – A new social movement – and a rich resource for doing things better.



Personal Budgets and Direct Payments – Carers making a difference and redefining ‘social care and support

[TLAP/POET Survey, 2014]

- **‘We’re co-producers and masters of innovation!’** Carers of all ages co-designing new patterns of care and support (better quality of life; improvements in physical health and well-being).
- **A key role for carers in local ‘market shaping’** (eg building community capacity, micro enterprises)
- **Integration:** New partnerships with health and housing and third sector .



Looking to the future: Solidarity matters!

[Standing Commission, NHS England and partners working together at London Zoo!]

- **‘Experts by experience’** – Carers recognised as vital to community and economy.
- **Carers of all ages and backgrounds are now part of a social movement** – activists but also partners with Government and with professionals.
- **A strong third sector** – innovation, challenge and peer support!



MONEY MATTERS! In an 'age of austerity' – we must make the economic case for investing in carers!

- **New estimates show that care provided by friends and family is now worth £119 billion every year.**
- Carers' contributions now far outstrip the total cost of the NHS (£98.8 billion).
- DH Impact Assessment suggests that each pound spent on support for carers would save councils £1.47 on replacement care costs and benefit NHS by £7.88.
- 1.2 million carers spend more than 50 hours a week caring – this is a workforce larger than the NHS!
 - [Carers UK/Leeds University and the RCGP]

And a final postscript that caring is much more than a 'budget' and a 'service'. It is about real lives, shared accountability 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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