

# Carers Rights? A new agenda for carers

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# 'Silent army' or 'Expert partners'? Who are the carers?

- **Over 6.4 million carers, (500,000 dementia carers, 118,000 young carers) .** Numbers expected to reach 9 million by 2037. Increasing numbers of intergenerational and distance carers. More carers of all ages providing often complex 'heavy end' care at home.
- **2.3 million carers give up work, 3 million reduce hours to care –** carers emphasise that best support would be quality care for their relative.
- **'Caring can be bad for your health' - 84% of carers report health problems 'related to caring'. 94% of carers say that caring has affected their mental health** (Carers UK survey 2013)
- **Number of carers providing unpaid care of 50 hours or more has increased by 26% over past decade.**

# WHO cares? Changing communities, an ageing population but higher aspirations for 'ordinary lives'.



# **Taking the carers' agenda forward – key priorities in the National Carers' Strategy 'refresh' [2010] and in forthcoming 'refresh of Action Plan [2013]**

- Early identification and support.**
- Enabling those with caring responsibilities to fulfil their educational/employment potential.**
- Personalised support for carers and those they support, enabling them to have a family and community life.**
- Supporting carers to remain physically and mentally well.**
- Ensuring young carers do not carry out inappropriate levels of care and can achieve in education and employment.**

# The Care Bill: A new agenda for care and support for carers

- **'Parity of esteem' for carers and those they support, with a new National Eligibility Framework** to give consistency across England.
- **Carers and users have equal rights to assessments and care plans.** We are first EU nation to formally recognise carers' rights as distinct (albeit inter-related) from those they support.
- **Underlying principles of 'well-being' and personalisation**— a culture shift in focus from crisis intervention to life chances and outcomes, with recognition of the need for integrated approaches from health, social care, housing and the welfare system.
- **Universal rights to information and advice** – with carers increasingly becoming both micro-commissioners as well as micro-providers [a huge role for the voluntary sector].

# Whole Family Assessment

- **The right to a carer's assessment and support plan (with the possibility of a *whole family assessment* if all agree).**
- **A new concept of FAMILY CARER and WHOLE FAMILY ASSESSMENT!**
- **Personalisation and Personal Budgets:** A shift to self directed support and a new flexibility in fitting services round people rather than people into services.
- **527,000 people and family carers now have Personal Budgets** (Personal Health Budgets coming in 2014) – most successful and most effective where there is local support. Most successful schemes use voluntary sector to identify need, plan support and use the budget separately.

# What carers told us they wanted, when ‘refreshing’ the Carers’ Strategy

- **Time out sometimes, if we get breaks, we are better carers!**
  - *‘There are times when I am so tired and upset, I could just walk away. Carers are part of the workforce. Shouldn’t we be entitled to some time out?’*
  
- **Listen to us and respect us! ‘Caring is not a career choice!’**
  - *‘I do everything to care for my husband at home after his stroke, yet when he goes into hospital, I am treated as ‘just the wife’ but in reality I am the real expert!’*
  
  - *‘I NEED to go to school – doesn’t my future matter too?’*
  
- **Early support, faster assessments – and ‘real care pathways!’**
  - *‘I feel I need to manage a web of services; the delays are endless and the assessments endlessly repeated. I feel constantly judged.’*
  
- **To be supported to look after our own health and well-being!**
  - *‘I need a gall bladder operation but I can’t leave my husband. Who will look after him? I am in pain, it affects my caring. I need care too!’*

# **‘Carer maintenance – carers are like cars, if you don’t look after them, they break down!’**

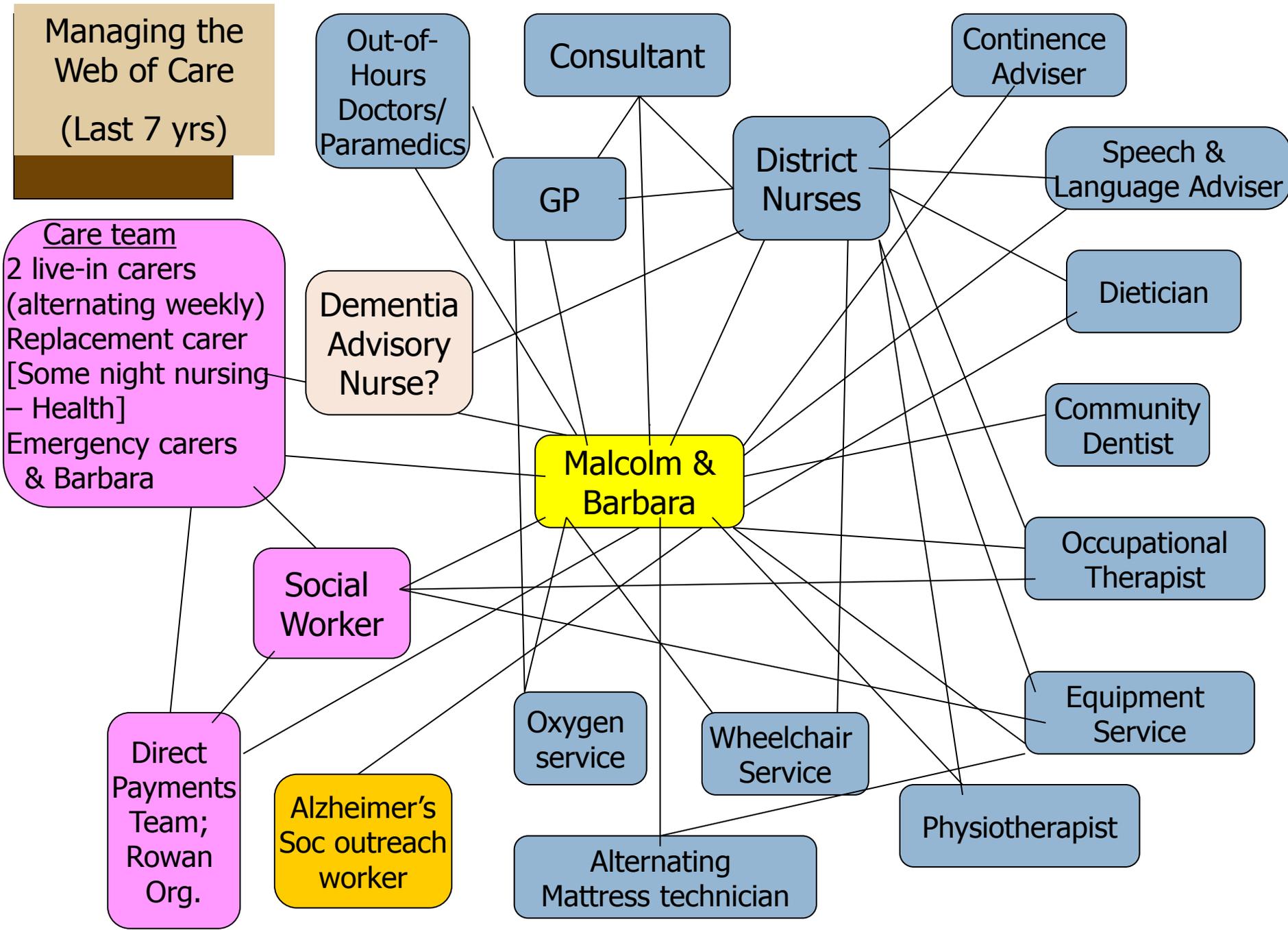
- **Strong evidence that supporting carers enables earlier discharge from hospital and keeps people at home.** Carers Trust/PRTC (*Supporting Carers, the Case for Change, 2012, The State of Care, Carers UK, 2013*) found that key factors in carer breakdowns and admissions/readmissions to hospital were:
  - **Relationships**, *‘not feeling being part of the team, not valued and supported – what would happen if I just walked away?’*
  - **Poor health, tiredness and interrupted sleep**, *‘families need maintenance too!’*
  - **High levels of intimate personal care**, *‘Nobody asked me what if felt like, going from a wife to a carer. I needed to say ‘I am here too’.*
  - **Frustration and lack of understanding of treatment or support.** Availability of ‘navigator’ or care coordinator highly valued but *‘Being a carer can mean losing your own identify – I am supposed to have retired but there’s no redundancy here!’.*
- **Creating the ‘expert carer’:** An Australian random controlled trial found that 3-5 sessions of personal care training to older carers (each lasting 30-45 minutes) resulted in a higher proportion of stroke patients achieving independence at an earlier stage and saved costs. Carers reported improved quality of life because they felt *‘confident and valued and understood the short, medium and long-term outcomes for the reablement programme.’* [Droes, R et al, 2006]

**Why we should think about carers' own health and well-being! Messages on carers' health checks from the National Carers Strategy Demonstrator Sites [University of Leeds, 2011]**

- ***'Looking after carers' own health should be a new priority for an effective NHS and social care system – they are the key members of the workforce!'***- 95% of carers receiving a health check felt the service was a good way to support carers.
- **Health improvements reported include:**
  - *'The way I look after my own health now – it was so good to talk about me for a change!' I feel much more confident, no more 'black holes'.*
  - *'My diet – it was dreadful, really I had stopped caring for myself!'*
  - *'My ability to cope with caring – I now feel the professionals are my partners not my enemies, asking more than I can deliver!' You need support from health AND social care to be a good carer!'*
- **A new role for public health and some key messages for Health and Well-Being Boards and local Health Watch**

## **‘Not an easy journey’ - when care and support are complex and multiple.**

- *‘Carers know better than anyone about managing complexity and the ‘web of care’ that is needed for someone with end-stage dementia, COPD or any one of those long term conditions which we now ‘live with’ rather than conveniently die from.*
- *If we communicate well with carers, then we have model project managers. We are the experts in care – if you let us. We’re very cost effective as well!’*
- [Courtesy Barbara Pointon, Ambassador, Alzheimers Society]



## The Dementia Challenge – Positive thinking about care and support and a culture shift from ‘*bed blockers*’ to ‘*lives worth living*’.

- **‘Dementia may be irreversible but it’s not the end of everything.** People and their carers can still live well, have fun, still engage with the world in new ways. This different path through life can produce some fascinating views – long-submerged happy memories perhaps, a newfound spontaneity that was never there before. It’s a journey, not an end in itself.’
- [Surrey County Council/Carers Action/NHS Surrey ‘Our Plan: Planning the Journey’]

# Age discrimination? Do we need a 'revolution in elder care'?

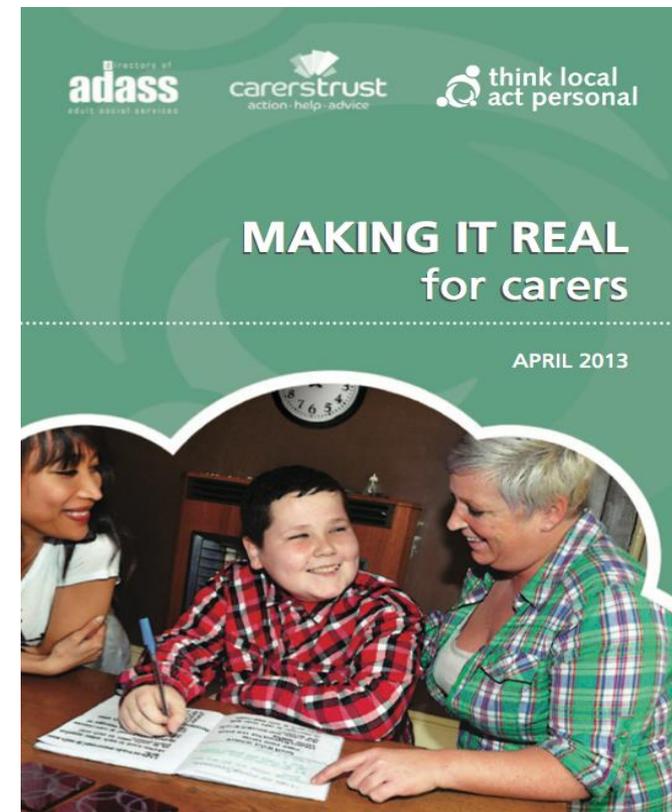
- **Majority of patients in hospital and community settings are over 75.**
- **84% of 435,000 people using home care services are over 75.**
- **2.5 million people over 75 have some kind of informal care from family carers or friends BUT...**
- **Older people's services do not currently have high societal status – and older people are themselves often carers through 'mutual caring'. 'Isolation' not only depressing but bad for health – strong messages about maintaining community services.**

# Personalisation – Making it real for carers and improving their experience of care and support.

- **2<sup>nd</sup> National Personal Budget Survey** (Think Local, Act Personal, May 2013) found that:
  - **70%** [of 3,3000 people] felt personal budgets ‘worked for them’.
  
- **Carers [of all ages] reported positive outcomes:**
  - **60%** reported a better quality of life;
  - **69%** reported that they received the support necessary to continue caring and remain well.
  - **52%** felt that their financial situation was better.
  - **53%** said that their physical and mental well-being had improved.

# Personalisation – ‘Making it real’ for Carers

- **Shaping the market: A spirit of ‘co-production’!**
  - Developing a new and more diverse ‘market place’ of provision *with* carers.
  - Developing (and resourcing) community assets.
  - New partnerships with voluntary sector.
- **Still some challenges for carers:**
  - Reliable information, advice [and brokerage].
  - Anxiety about management.
  - Concern about finding support.
  - Anxiety at possible loss of ‘traditional’ services.
  - Managing transitions.



## **‘Emotion, Space and Society’ – Using community assets to create carer friendly communities.**

- **‘Shared lives - Isolation and loneliness’** – frequently cited by carers and users as major problem. New study from University College, London found isolation major cause of premature mortality and morbidity (26%).
- **Creating carer friendly communities:** Stevenage building on dementia challenge – and more – to proactively encourage greater accessibility and support for carers to use mainstream provision.
- **Understanding 21st century carers’ lives:** Growing number of carers of working age (and growing number of younger carers with expectations of an active adult life) – supporting access to education, training, employment (and acknowledging both the timescale of modern caring and the often multiple caring needs in the family).

# 'A home life?' – Welcome recognition in Care Bill of importance of housing as a service

- **A major policy shift from hospital to home** (focus on reablement, better discharge arrangements, 'virtual wards', broader role of GP as '*champion for patients and carers and a gateway to the system*')
- **But getting home (and staying home) still a challenge.**
- **New opportunities in creating provider networks**, working in partnership with private and voluntary sector partners.
- **Housing options** (from handyman services to extra-care housing and using care homes more creatively as community assets.)



**‘The key to dignity and respect – let’s all listen to the carers.  
We’re professionals too!’** [Young Carers Group, 2013]

- **‘Creating age appropriate carer friendly services – we need a new ‘listening’ culture for younger AND older carers! Where’s the Equality Act? There’s too much age discrimination.’**
- **‘ASK the carers – what would make a difference to our lives?’**
- **‘Think family – don’t assess us in isolation.’**
- **‘We want to care, but understand that we still have a lot of life to live!’**



# The way forward .....

- **We need to invest in new services and models of care (which build family resilience but value and support caring as integral to lives worth living).**
- **Innovation and integration:** Empowering carers and users to make informed choices and help shape the design and delivery of local services – integration around individuals rather than integrating individuals into services is key to better outcomes – and management of scarce resources.
- **Supporting a diverse market place for care and support** [OECD (2012) notes that need for social care creates employment – but we have to raise the profile of care and support as jobs worth doing].

# And a postscript on the ‘elephant in the room’ – paying for social care

- **Government response to Dilnot:** First steps towards a ‘fair and reasonable’ national policy on paying for care and support.
- **Total expenditure on long-term care services (including health, social care and disability benefits) currently 1.6% of GDP (£20.6 billion).**  
Private expenditure on care is currently £6.8 billion.
- **We need a wider debate on personal and public responsibility for care and support** (and incentives for families to ‘invest in the future’ and co-produce some very different models of care and support).
- **Valuing carers!** 80% of care currently provided through families (with escalating complexity and timescale of caring.)

## And a postscript about resources

- **Between 2011 and 2015** (as part of the Government's response to the Carers' Strategy) an additional £400m has been allocated to PCTs and now CCGs to improve support for carers of all ages.
- **Councils also receive a Carers Grant** in their general local government allowance grant.
- **Funding to support Care Bill** – Phased over 5 years, rising to £175m a year.
- **Carers estimated to save Councils/NHS up to £119b a year** – supporting their role, Co-producing planning and best use of resources, is an investment in the future!

**And a final reflection — carers' needs for care and support change over time. Our challenge is to create a system which manages transitions, respects choice and maximises assets!**

