

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!’

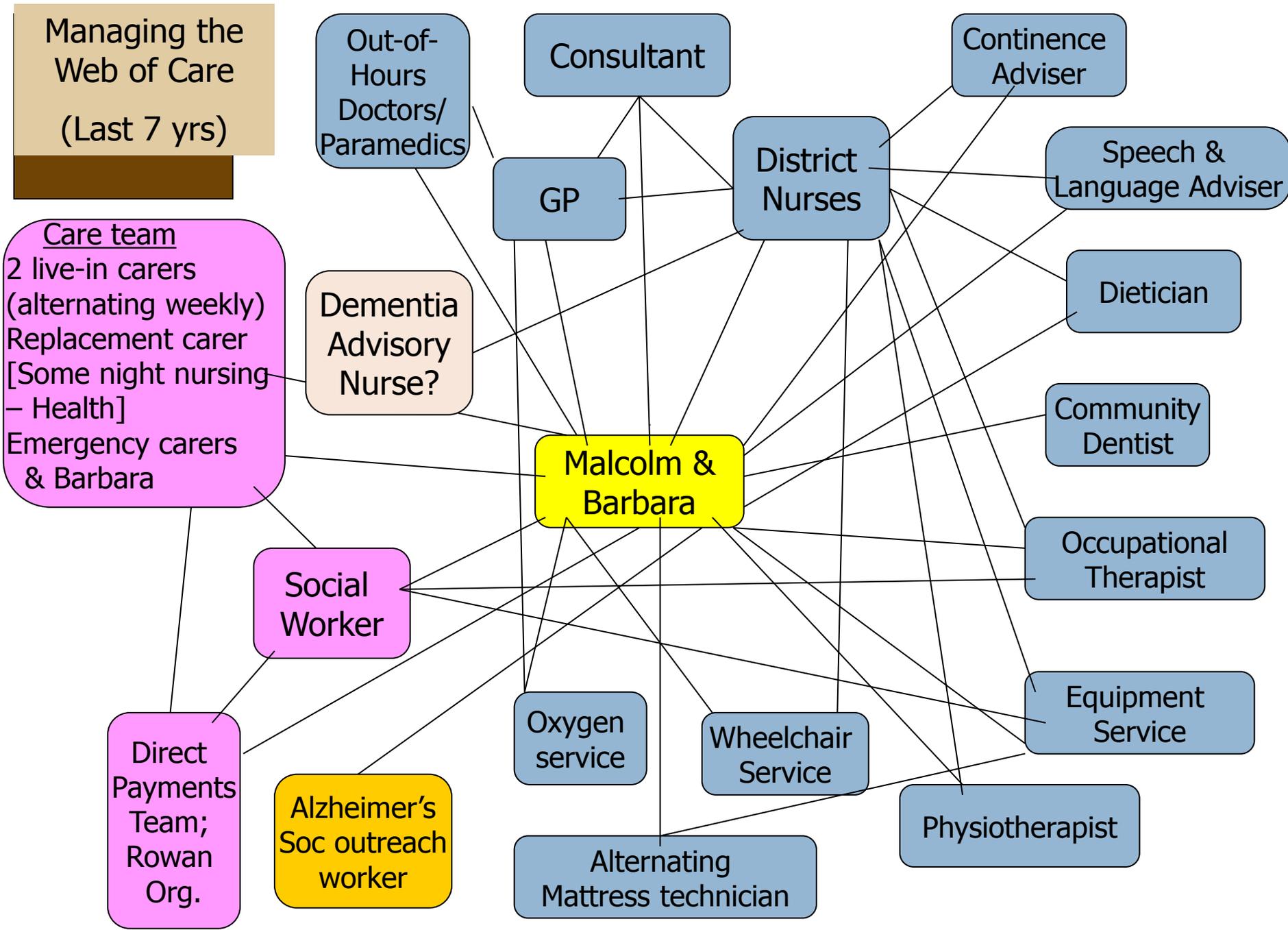
- **Strong evidence that supporting carers enables earlier discharge from hospital and keeps people at home.** Carers Trust/PRTC (*Supporting Carers, the Case for Change, 2012, The State of Care, Carers UK, 2013*) found that key factors in carer breakdowns and admissions/readmissions to hospital were:
 - **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 it 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 identity – 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.**

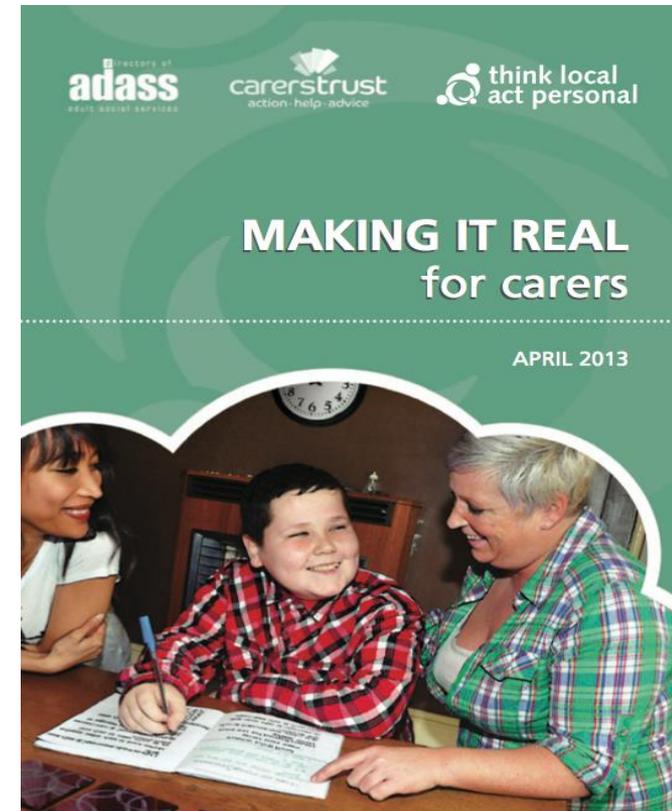
Personalisation – Making it real for carers and improving their experience of care and support.

- **2nd 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!

