

Dementia Action Alliance



The Carers' Call to Action – Overview

What is The Carers' Call to Action?

- Leading national charities, public bodies, family carers and private providers came together in 2013 to address the intolerable situation that many people experience when a loved one is diagnosed with dementia.
- ***'A diagnosis of dementia is given not just to one person – it is given to a spouse, a partner, a child, the extended family and friends. It is important to remember that every time a diagnosis is made it is life changing. It is therefore vital that everyone has timely access to bespoke post diagnosis support and information on an on-going basis.'*** Alistair Burns NHS England National Clinical Director for Dementia
- Support across England continues to fall far short of what is needed – There are approximately 3,000 Macmillan nurses compared to about 102 Admiral Nurses – one in three people will be diagnosed with cancer in their lifetime (Cancer Research UK). It is estimated that one in three people will care for a person with dementia in their lifetime (Carers Trust).
- ***"I was falling apart, trying desperately to think up new ways of coping and feeling really isolated. We were not on a pathway, we were stumbling. I needed support but had no idea how to get it or what it would look like."***
- Mounting research demonstrates the value of supporting carers both to the person with dementia and to the efficient use of scarce public resources - ***'including and supporting carers of people with dementia will lead to better outcomes for patients, carers and ultimately the professionals supporting them'*** (Triangle of Care Carers Trust & the Royal College of Nursing 2013)
- Carers save the economy £119 billion a year. Properly identifying and supporting carers will prevent escalation and demand on statutory services (Carers Trust 2013)
- The new Care Bill, Better Care funds, Health & Social Care Integration, Health & Wellbeing Boards, 'meaningful local engagement with patient voices' and The Dementia Movement provide new opportunities to engage and for commissioners to fund and deliver better early intervention and support.

- We have created 5 aims supported by a 20 point checklist of what good support for the needs and rights of family carers must look like.

‘our shared vision’

Aim One –

Family carers of people with dementia have recognition of their **unique experience** - 'given the character of the illness, people with dementia deserve and need special consideration... that meet their and their caregivers needs' (World Alzheimer Report 2013 Journey of Caring)

Aim Two -

Family carers of people with dementia are recognised as **essential partners** in care - valuing their knowledge and the support they provide to enable the person with dementia to live well

Aim Three –

Family carers of people with dementia have access to expertise in dementia care for personalised information, advice, support and co-ordination of care for the **person with dementia**

Aim Four-

Family carers of people with dementia have assessments and support to identify the on-going and changing needs to maintain **their own health and well-being**

Aim Five –

Family carers of people with dementia have **confidence** that they are able to access good quality care, support and respite services that are flexible, culturally appropriate, timely and provided by skilled staff for both the carer and the person for whom they care

What we need you to do

- **Encourage others to SIGN UP** at: www.dementiaaction.org.uk/carers - we can only do this together!
- Please **download the ‘We Support’ logos** http://www.dementiaaction.org.uk/carers/download_cc2a_logos and add to your website and printed materials
- We **MUST engage with Health and Wellbeing Boards and Commissioners** to bring about change.
- Please **tweet on twitter** – our hash-tag is #DAACC2A and our user name is @DAACarers
- If you are able to offer anything practical for example fundraising, social media, time, experiences, stories, money! Please get in touch.
- Write to your GP/Clinical Commissioning Group/Health and Wellbeing Board/MP/Local Authority/District Council/ etc. highlighting The Carers’ Call to Action and five aims of **our shared vision**. Template letters are available at: <http://www.dementiaaction.org.uk/carers>
- Let The Carers’ Call to Action team know about examples of carer’s support that works well in

your area

- Embed the five aims of **our shared vision** in your own service development strategy.
- Work within your local community to increase awareness of the needs and rights of carers of people who have dementia – this may include fundraising for carers support groups, talking to local groups etc.
- Make everyone within your strategic networks aware of the needs of carers and The Carers' Call to Action.
- Work locally to collate an overview of services and identify where there are strengths and gaps.
- Share your story to highlight the need for The Carers' Call to Action
- Commit to time to speak to people/organisations/commissioners about The Carers' Call to Action (slides are available to download from the website)
- If you have experience of caring for someone with dementia and you would be happy to talk about it at meetings, events or conferences we can support you to do this!
- Slide templates are available on the website, which we encourage you to use to present at every possible opportunity the aims of our shared vision.
- If you need copies of our leaflets let us know.

What good support looks like - Do you commission?

- 1) **Pre-diagnosis support** from the point of GP referral to Memory Clinic.
- 2) **Post diagnosis education** for the family and person with dementia.
- 3) A **dementia adviser/support worker/Admiral Nurse/** to provide on-going & timely access to local, face to face, **personalised, dementia expertise** and practical advice as well as psychological & emotional support.
- 4) On-going & timely access to dementia specific **local information, resources and support** in a variety of accessible formats.
- 5) Support for family carers that provides a clear, **collaborative pathway of action and plan of care** once **GPs** have identified a family carer (QOF April 2014.)
- 6) **Carer Peer Support Groups** specifically for family members/carers/friends of people living with dementia, which meets the cultural needs of the local population and age range of those affected.
- 7) Health and social care staff (including third sector services) who have **knowledge & expertise in dementia** to complete personalised assessments of a person who has dementia and their family carer's.
- 8) An **expert clinician in dementia** to support and supervise Care Co-ordinators/Social care staff/Health Care Practitioners with their role in assessing, treating and managing the impact of co-morbidities of the person with dementia and thus supporting the family carer.
- 9) **Support to remain active and integrated** in the local community thus reducing impact of loneliness and social isolation of both the person with dementia and their carer e.g. dementia friendly communities, health prescriptions, community transport, age appropriate activities.
- 10) Access to appropriate and timely **respite** opportunities by the hour, day or week in a range of settings.

- 11) Age appropriate support for the impact of **young onset dementia** e.g. supporting younger family members, loss of income and roles.
- 12) Culturally appropriate, accessible information and support for people with dementia and their family carers from **Black and ethnic minorities** communities.
- 13) Culturally appropriate, accessible information and support for people with dementia and their family carers from **Lesbian, Gay, Bisexual and Transgender** communities.
- 14) Dementia **advocacy** services – e.g. to capture the wishes, values and beliefs of a family carer and strategies to ensure people living with dementia have a person-centred assessment, support for completing legal and financial issues.
- 15) Community **Health & care services** that are delivered by those who have training & expertise in dementia (not just dementia awareness) e.g. dentist, nutrition, opticians, podiatry, hairdressers who specialise in dementia and offer domiciliary visits.
- 16) **Training in dementia care** for Health & Social Care professionals.
- 17) **Glossary/overview/Jargon buster** concerning what professions/services mean and what they can do for you.
- 18) **Dementia awareness** promotion within local communities and businesses including Dementia Friends, Dementia Friendly Communities/Environments, Local Dementia Action Alliance initiatives.
- 19) Support for **employers** to enable carers to continue working.
- 20) Support, and training as necessary, for family carers and people living with dementia to **have a voice** to influence and support change locally. This requires a '**meaningful community engagement**' so that commissioning services is based on the evidence of need of the local population.

Essential Reading:

Alzheimer's Disease International, BUPA (2013) *World Alzheimer Report 2013 Journey of Caring An Analysis of Long-Term Care for Dementia* (Alzheimer's Disease International, London)

Alzheimer's Society (2013) *Dementia 2013: the Hidden Voice of Loneliness* (London, Alzheimer's Society)

British Institute of Human Rights (2012) *Your Human Rights - A Pocket Guide for Carers* (British Institute of Human Rights, London)

Carers Trust (2013) *A Road Less Rocky – Supporting Carers of People with Dementia* (Carers Trust, London)

Carers Trust, Royal College of Nursing (2013) *The Triangle of Care – Carers Included: A Guide to Best Practice for Dementia Care* (Carers Trust, London)

Carers Trust (2013) Carers' Hub Toolkit for Commissioners

Carers UK (2014) Supporting employees who are caring for someone with dementia

Red & Yellow Care (2014) A Good Life With Dementia

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Follow us on **Facebook** DAA The Carers' Call to Action

Visit our **webpage** www.dementiaaction.org.uk/carers

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NB: To Follow: Examples of good services