Supporting the needs and rights for family carers of people with dementia through our shared vision.
EXECUTIVE SUMMARY

Introduction:
At least 670,000 people in England have dementia and this number is set to double in the next 30 years. It is estimated that at least 550,000 people act as primary carers – this by no means reflects the number of children, extended family and friends whose lives are also affected. Caring for a loved one with dementia is one of life’s hardest challenges. Despite their numbers and needs, carers often care alone. Support is too often provided late and focused on costly and stressful crisis management. This needs to change.

Why we need a Call to Action now
Carers saved the UK economy £7 billion a year and deserve a better deal.

- The rapid increases in the numbers of people living with dementia and those that care for them mean that current models of support are unsustainable.
- New commissioning structures and an agenda to increase integration and localisation of services provide new opportunities to deliver better more cost-effective support services.
- Mounting research demonstrates the value of supporting carers both to the person with dementia and to the efficient use of scarce public resources.

What is The Carers’ Call to Action?
Leading national charities, public bodies and private providers are coming together to meet this challenge through the Carers’ Call to Action. They will be providing a coherent, coordinated and concerted response to this intolerable situation.

Phase 1
The Dementia Action Alliance will approach Health and Wellbeing Boards, Clinical Commissioning Groups and Local Government across England to highlight the importance of carers of people with dementia and ask them to sign up to our shared vision below:

Carers of people with dementia:

- have recognition of the unique experience of caring for someone 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
- have access to expertise in dementia care for personalised information, advice, support and
co-ordination of care for the **person with dementia**

- have assessments and support to identify the on-going and changing needs to maintain their own health and well-being

- 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

**Phase 2**

The Dementia Action Alliance will work with leading Health and Wellbeing Boards to create a picture of what excellence in carer support looks like.

**What you can do?**

- Write to your Health and Wellbeing Board and ask them to sign up to the shared vision

- Sign-post the Carers’ Call to Action team to examples of carer support that works well in your area

- Join the Carers’ Call to Action and align your work programme to fellow DAA member carer initiatives

**Simon Kitchen**

**Executive Lead - The Dementia Action Alliance**

**November 2013**
Imagine the loneliness when the person closest to you no longer remembers your birthday or their own.

Imagine when they stop recognising the home you’ve shared for many years, cannot recall key memories of your life together – and one day perhaps they don’t even know you or their own children.

Imagine continuing to love and care for them on your own every day all day, when those looking on from outside don’t notice or understand any change.

Imagine doing your best to keep them safe and well, when they can’t see or accept their own vulnerability and may be antagonistic to your efforts or sometimes lash out.

Imagine when friends and family stop coming round, because they can’t cope with the changed “atmosphere”, don’t know what to say, are embarrassed, offended, or scared by unpredictable behaviour.

Imagine when bodily functions can no longer be controlled.

Imagine trying to communicate when the person you care for reverts to their original ethnic language or stops talking altogether.

Imagine when parent becomes child, partner becomes patient, you become a carer.

Providing timely support, information and respite can make the difference between swimming and drowning.
INTRODUCTION BY ALISTAIR BURNS (NHS ENGLAND’S NATIONAL CLINICAL DIRECTOR FOR DEMENTIA).

I am privileged to support the Dementia Action Alliance - The Carers’ Call to Action.

We have a rich research and evidence base for the need to support carers of people with dementia and we must now be creative and flexible and take action (In using the term ‘Carer’ I am referring to the estimated 550,000 unpaid family or friends who have a caring role – one in three of us will care for a person with dementia in our lifetime.)

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.

Simply giving information is often not enough and people providing the information will need to recognise that the needs of an individual will change; their ability to cope will alter and this commitment must be for the entire dementia journey.

The emphasis on support for carers is rooted in the fact that the latest research highlights that caring for a person with dementia is recognised as one of the most stressful care-giving experiences. Every day I meet people and am humbled by their stories. Frequently I hear carers say that they would have coped better or they would have treated people differently if they had only just understood what dementia is. People without support may unknowingly drift into crisis and one recent report suggested that 77% of families experience relationship or emotional upset within the 18 months after diagnosis.

The Carers’ Call to Action will highlight a number of issues where life, dignity or sense of self-respect is put at serious risk in a caring role. It will provide examples of good practice and, solutions (often very simple and inexpensive initiatives), which can enable carers to access local information and support as needed.
A Carer may make the difference between a person living well with dementia or not. As Tom, a person with dementia observed recently 'I’m very happy I’ve got someone behind me who keeps the balls in the air – and that’s my wife…although I do upset her sometimes'.

The pivotal role of carers in achieving a good quality of life for people with dementia makes this Call to Action so important. As NHS England’s National Clinical Director for Dementia, I will give it my full backing.

Professor Alistair Burns
November 2013
DEMENTIA ACTION ALLIANCE (DAA) –
THE CARERS’ CALL TO ACTION (CC2A):

The Case for Change:

The CC2A is responding to a challenge we can no longer afford to ignore. We will be supporting everybody, working in partnership across all organisational boundaries, to ask the right questions, explore examples of good practice and find solutions to address the needs and rights for family carers of people with dementia.

There are approximately 670,000 people living with dementia in England. This number is set to double in the next 30 years. Currently 550,000 people act as primary carers for people with dementia. If carers of people with dementia are not themselves supported, how can they go on caring (and saving the nation an estimated £7 billion per year – PM’s Challenge on Dementia, March 2012) without coming to breaking point? Leaving carers to cope under enormous pressure is a false economy – with far greater long term costs. The actual knock-on health and social care costs for the unsupported carer are not as yet recognised. If a carer is identified and well supported there are significant potential savings to health and social care by not providing expensive services for the person with dementia. There will also be improvement in the quality of life for families as a whole including the person with dementia.

‘Unlike most other chronic conditions, people with dementia can develop needs for care in the early stages of the disease, and become increasingly reliant on caregivers throughout the course of the disease…given the character of the illness, people with dementia deserve and need special consideration in designing packages of care and support that meet their and their caregivers’ needs’ (World Alzheimer Report 2013)

Carers of people with dementia need recognition and support - The true impact on carers of people with dementia can be difficult to convey. Professionals may encounter the situation for less than an hour at a time. Carers’ needs rarely fit into tick boxes or a typical pathway. Finding help and support through a system that seems to be obtuse and complicated, takes time and energy. Most carers have little of either. New challenges and sudden changes, often together with sleepless nights, leave many carers feeling that they cannot cope.

“It sometimes feels as if I am going through a period of bereavement. I have lost the man that I chose to spend the rest of my life with. He looks almost the same but is not the same.”
“Caring for my husband was the most lonely, demanding and traumatic time of my life.”

“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.”

“Everyone – I mean everyone - from the professionals to my friends and family, the community as a whole, thought caring was a natural thing. I didn’t even have a pet growing up – I had never cared for anything. All of a sudden I was an expert! I was ashamed that I found it so hard. My father was the man I loved above all others – it shouldn’t have been so hard.”

“It felt that I was failing at every single thing, every day no matter how hard I tried. It was just unrelenting and remorseless. I was being condemned by the perceptions of the Asian community and the statutory bodies. There was no one on my side when I needed it most. It is a very dark and lonely place to be.”

**Carers of people with dementia experience high levels of strain and distress** – ‘Given the character of dementia - the impact of cognitive deterioration and personality changes,- carers experience a succession of losses and bereavements over many years of caring’ (Moise, Schwarzinger and Um 2004). Caring can take place over 10-15 years, requiring an intensity of vigilance, physical care and emotional support 24/7 from the carer, often with little outside help.

“He has in many ways become a stranger, who has become suspicious and untrusting. I am always apologising on the bus, for his disinhibited and provocative behaviour and trying to keep the peace when people get offended … it is sad and exhausting.”

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Carers of people with dementia are often older people themselves - In a recent study, 65% of older carers stated they have long term health problems or a disability themselves and 49.2% said their health had deteriorated in the last year (Alzheimer’s Society 2013)

“My mum had to go into hospital suddenly – it turned out that she had been putting off going to the doctor because she knew something was wrong with her, but was so worried about my Dad. She needed back surgery and had advanced heart disease and had a stomach bleed from taking aspirin so they couldn’t operate. When my Dad went into a care home they had to hoist him and he couldn’t do anything for himself. My Mum didn’t have a hoist or a care package at home. I feel terrible that I never knew”

Younger people get dementia too - 17,000 people with dementia are under the age of 65 – Early onset dementia (under 65) is likely to generate a multitude of needs requiring specialist responses.

“We were in our 50s and both still working – my wife was a secretary and she lost her job because of the
difficulties she began to experience. Quite soon it became clear I couldn’t leave her alone at home, but finding support and services which were suitable for a lady in her 50s was nigh on impossible.”

Many carers have to leave work or reduce their hours, losing their independent status, income and security, colleagues and perhaps ultimately their own identity – Carers can be partners, children or friends

There is evidence that the chances of a family carer having paid work outside of the home decreases by 10% with every 1% increment in hours of personal care provided (OECD 2011).

“I enjoyed showering Yvonne and getting her dressed and took great pride in seeing that she was still dressed in the manner that she was used to I didn’t want help for this as it was the only opportunity for intimacy left between us. I tried to carry on working and caring for Yvonne but the stress building up inside me as I was trying to look after her and earn a living became unbearable. It affected my health and my ability to work and we nearly lost everything, our home and my business.”

Carers save the economy £119 billion a year and properly identifying and supporting carers will prevent escalation and demand on statutory services (Carers Trust 2013)

Carers are crucial in supporting people with dementia to stay independent for as long as possible - When the dementia advances the right support can delay admission to hospital and residential care with the resultant high costs. 70% of acute hospital beds are occupied by older people, approximately 40% of whom have dementia (Royal College of Nursing 2012). Two thirds of people in care homes at any one time have dementia (Counting the Cost Alzheimer's Society 2010) With the right support, carers can care for longer and care homes can become a choice rather than a desperate final solution at a time of crisis. Carers, and importantly the support of carers, must become an integral part of the care and support package

“Dad was an independent man and lived on his own, he went dancing, walked familiar routes and looked after his garden but he was becoming severely impaired by his dementia. One day he forgot his key and was found much later sitting in a very hot greenhouse with his coat on. We wanted to maintain his independence whilst managing the risks, it was a stressful time.”
Carers need to be supported whilst making difficult choices about care -

“I’d made a commitment ‘for better or worse in sickness and in health’ – the decision for my husband to go into the care home was the most difficult decision of my life. I know he is well cared for, but every day I wake up feeling guilty and lonely and every night I go to sleep feeling lonely and guilty”

“They don’t make it easy for you do they? I was tearing my hair out, worried about how we could afford it and then there was all the stuff on the television about abuse in care homes.”

“I was angry when social services didn’t understand the need for my father to be placed in a care home, for respite, that met his cultural and language needs as he had reverted back to his original ethnic language. I felt completely let down by their lack of understanding”

Diagnosis, information and support must go hand in hand so that people are not left struggling and unable to make important decisions early on.

When carers are well-supported, they can provide better care for the person they care for and report better well-being outcomes themselves (Ablitt, Jones and Muers, 2009). Timely support for carers results in better care for the person with dementia and is therefore excellent value for money.

‘Increasing the coverage of caregiver multi-component interventions (support, education and training), early in the course of the illness. There is a strong evidence-base that such intervention is highly effective in reducing caregiver strain, delay and reduce rates of transition into care homes’ (World Alzheimer Report 2013)

Barbara Pointon speaks honestly about her experiences when caring for her husband Malcolm – “An aggressive response is often the result of a carer’s bossiness or impatience or of the person themselves misunderstanding the reality.” She reflects “If they can’t enter our world we must enter theirs and affirm and enjoy it” (with reference to ‘And Still the Music Plays’ Graham Stokes)

Supporting carers to effectively manage the present and plan and prepare for the future -

“It often felt like a battle getting the help and support we needed, when I wanted to be spending quality time caring for my husband.”
Carers need to be seen as essential partners in care. The person they care for will often quite quickly lack the ability to convey their wants and needs or indeed be unaware of their declining capacity and be resistant to help. It inevitably becomes the carer’s responsibility to represent and advocate for the person with dementia, to ensure they remain safe and well and are treated with dignity & respect by others.

‘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)

“One doctor even said “If he is not willing to cooperate then there is nothing we can do”. I explained that he had dementia but security was called and we were escorted out of A&E into the car park. I was so upset. We needed help understanding and compassion… but he was treated like a troublemaker.”
The needs of carers of people with dementia must be recognised - Carers tend to put their own needs last. It is therefore vital for us to reach out proactively to them, to offer appropriate, timely support and information to enable them to avoid collapse and breakdown.

A Road Less Rocky (Carers Trust 2013) highlights good examples of where ongoing, effective support is provided but frequently highlights where it is unavailable - Someone to help me steer through all those sickening peaks and troughs in the early days would have been invaluable

“I built up a brick wall and tried to do it all myself, hiding behind a mask that everything was ok but it wasn’t. My Admiral Nurse skilfully and gently chipped bits away. I learnt to trust her and because of her actions I realised that if I wanted to be an effective carer, which I want to be, I’ve got to acknowledge that I have needs and I’ve got to do something about it and to ask for help.

In order to continue their caring role, carers need timely breaks that meet their needs as well as the person with dementia - “It is mentally exhausting, and I am stuck in ‘Groundhog Day’ as every day is the same, draining grind, with no change in sight for the future. I feel my life is over. Time out is what I need.”

'Triangle of Care'
The Carers’ Call to Action supports the Articles of Human Rights, which are fundamental benchmarks that must be adhered to. Human Rights law imposes duties on the state and on those who provide services to ensure that carers and the people they care for are treated fairly and with proper respect for their dignity.

The key rights for Carers are:

**Article 2 – Right to Life** – for example:
- Breaches of right to life may occur when a judgement is made that because somebody has dementia or is an older person medical intervention is withheld.

**Article 3 – Right to be free from inhuman and degrading treatment**
- Carers lacking support who suffer from severe physical or mental health illness as a result of caring (NB when the authorities know about it)

**Article 8 – Right to respect for private and family life, home and correspondence** – for example:
- Carer’s own health needs - physical and mental well-being
- Carer’s loneliness and isolation - being able to participate in life in the community
- Carer’s Choices – to be able to make choices about the things that affect you
- Carer’s relationships – maintain and establish relationships.


**Social Outcome Return on Investment:**

The situation is not sustainable. Dementia already costs the UK economy £23 billion a year, but carers of people with dementia save the economy £7 billion (Prime Minister’s Challenge on Dementia, 2012). Yet, the evidence shows that many carers are struggling to fulfil their caring role. Research from Alzheimer’s Society (Support.Stay.Save, 2011) found that 52% of carers had insufficient support to carrying out their caring duties and this had a negative impact on their physical and mental health. This in turn exacerbates the needs of the person with dementia and leads to a greater need for intervention and a greater burden on the NHS, social services and individuals as they reach crisis point. The simple fact is that if carers are supported, the person with dementia can live well with their condition, preventing the need for costly intervention measures.
This is corroborated by evidence from the Princess Royal Trust for Carers. Their research found that a small investment can make a fundamental difference and represents a significant long term financial saving. An investment of less than £5 million in carers’ services resulted in at least £73 million worth of social gains in a year. (The Princess Royal Trust for Carers - Carers’ Centres: What impact do they have? 2011)

Furthermore, nearly one in five carers is looking after a person with dementia in their family and these carers are also more likely to combine their caring role with full time employment (Carers UK, 2013). The Carers UK report, The State of Caring 2013, found that 56% of all carers, who had to give up work to care, spent 5 years out of work as a result. At the moment, there is little evidence on the numbers of carers in work who are affected by dementia. Potentially, there could be a large workforce, not in employment, as they are caring for a person with dementia. Employers for Carers is currently undertaking ground breaking research in a bid to prevent a drain of workforce experience and skill through increased demand for care as the prevalence of dementia increases.

The immediate financial impact on carers is profound. The report Carers in Crisis (Carers UK, 2008) found that nearly two-thirds of carers live in fuel poverty and just over half of carers are in debt. However, the impact can be felt even after the carer no longer has a caring role. If a carer is no longer in work, they cannot contribute to a private pension scheme. In addition, as the pension age rises, carers can find that they have to wait longer to claim their state pension.

‘Additional investment through direct payments for family caregivers and improved pay and conditions for paid carers is likely to repay dividends – greater stability of the paid caregiver workforce, reduced caregiver strain, and better quality care.’ (World Alzheimer Report 2013)

‘Integrated Care and Support: Our Shared Commitment’ (2013) calls for ‘improving the experiences and outcomes of individuals and communities’

In order to achieve a better quality of paid care it is essential that the care workforce receive appropriate dementia training and training in care, compassion and empathy. The new strategy for nursing, midwifery and caregivers focuses on relationship based care across the whole care system. The strategy highlights the 6Cs: care, compassion, competence, communication, courage and commitment. Improving the quality of paid care will increase the confidence for paid care services to be used for respite and personal care needs.
'On my dad ... My dad was very lively intelligent late 70 year old when we first started noticing a problem. He would forget things, lose things his behaviour became more erratic and he didn’t trust people…. even his family. We cared the best we could; he lived in an isolated cottage so it was a worry. We got paid carers to come in too but eventually as his situation got worse we realised he would need specialist 24/7 care. Fortunately we found a good care home that was a ‘care’ home and he settled in well. He played his music in the home right to the end; he said it gave him freedom. He became gentle and caring himself as the dementia got worse and he was always glad to see us even though he wasn’t sure who we were. The dementia took its toll on the family, it wore us down but we stuck together for him and we did our best and at the end of the day that’s all you can do’ Tony Husband (Cartoonist)
Our shared vision:

Leading charities, public bodies and private providers have come together to bring about a crucial change for family carers of people with dementia. We must continue to work together to turn our shared vision into reality.

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)

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

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

- have assessments and support to identify the on-going and changing needs to maintain their own health and well-being

- 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

These five ambitious aims will bring about real and lasting change. When this is achieved, we will ensure carers are acknowledged and respected as essential partners in care, and are supported with easy access to the information and the advice they need to assist them in carrying out their role.

Achieving our shared vision we will:

- Have a major impact on people with dementia and family carers.
- Increase choice and quality of life.
- Reduce the risk of expensive and distressing crisis intervention.

We need your support. Join us to make it happen – The Carers’ Call to Action will support you!

Share our vision!!
MILESTONES

- By March 2014 CC2A will engage with all Health and Wellbeing Boards, Clinical Commissioning Groups and Local Government in England to make a commitment to our shared vision. We will provide support, resources, examples of good practice and solutions.
- By March 2015 two thirds of Health and Wellbeing Boards, Clinical Commissioning Groups and Local Government in England will recognise the importance of support for carers of people with dementia.
- CC2A will produce a free booklet highlighting the key issues, questions and actions everyone can take within their local community to support the needs of carers of people with dementia.
- CC2A will ask individuals and organisation to ‘sign up’ to commit to ‘our shared vision’

Context

The Prime Minister made his personal commitment to improve the lives of people living with the condition in his Challenge on Dementia (DH 2012). We strongly believe that we now need to focus on the need of carers with people with dementia. If carers have the right support, the quality of life of people with dementia will greatly improve.

We know that there are good and often inexpensive solutions delivering the services that are needed to bring about significant and lasting change. We do not need to re-invent the wheel – we need to join up the dots.

In order to attain our shared vision we need to propose solutions, which will make it achievable. The DAA absolutely needs to be one united body to drive this regardless of organisational and political boundaries – the message has to come from and represent all members in partnership.

- Dementia is a national priority for the coalition government – Prime Ministers Challenge on Dementia with cross-party support.
- Supporting carers of people with dementia is crucial for maintaining both the wellbeing of the carer, the person with dementia and reducing the financial cost on local public services.
- Health and Well-being Boards (including CCGs and Local Authorities) are the key bodies who will shape the priorities and agenda locally.
• **The DAA** has over 650 national and local members, many of whom will be engaging with Health and Wellbeing Boards from a variety of different perspectives.

• The need for change is strongly demonstrated in the Carers Trust report—‘**A Road Less Rocky – Supporting Carers of People with Dementia**’ (2013)

• The World Alzheimer Report ‘**Journey of Caring - An Analysis of Long-Term Care For Dementia**’. (2013) recommends that Government needs to ‘acknowledge the role of caregivers and ensure that there are policies in place to support them.’

• ‘**Triangle of Care – Carers included: A Guide to Best Practice for Dementia Care**’ is due to be launched by the end of 2013 (Carers Trust and Royal College of Nursing 2013)

• **Dementia Movement Campaign** (Public Health England and Department of Health)

• **Dementia Mission Fulfilment Journey** – ‘Helping a loved one with dementia’,


• ‘**NHS Commitment for Carers**’ – a series of commitments from NHS England to ensure that carers are recognised, valued and supported.

• **Public Health England and NHS England timely & post diagnosis strategy.**

• **Public Health Outcomes Framework** – Outcome 1: Increased healthy life expectancy (including health quality) and Outcome 2: Reduced differences in life expectancy and healthy life expectancy between communities.

• **NHS Outcomes Framework & Adult Social Care Outcomes Framework** – Domain Two (Enhancing quality of life for people with long term conditions) including that dementia ‘diagnosis rates is not the direct measure sought, a secondary complementary measure is being developed which will measure the effectiveness post diagnosis care in sustaining independence and improving quality of life’

• **Integrated Care and Support: Our Shared Commitment** – a concordat signed by 14 organisations including ADASS, CQC, LGA, Monitor, NHS England, HEE, NICE, PHE, SCIE, TLAP and National Voices for a ‘more integrated approach across the entire health and social care system’
• **Integration Pioneers** – aims to make health and social care services work together to provide better support at home and earlier treatment in the community to prevent people needing emergency care in hospital or care homes. The Integration Transformation Fund (ITF) will be available for groups of GPs, Hospitals and other healthcare providers to apply to fund new services as long as they plan to collaborate with social care providers. The money should be used for early intervention and to prevent illness deteriorating to a critical point.

• **QOF** - People need timely support and information to reduce the risk of crisis and therefore save the economy billions of pounds each year. There is a proposed new QOF indicator for April 2014 to actively identify family carers of people with dementia.

• **Local Government Association** – ‘Rewiring Public Services’ – ‘recognising and supporting the crucial role of family, carers and neighbours in keeping people independent and within their community.’

**WHAT WE WILL DO:**

We acknowledge the unique and bespoke needs of local areas in England. Therefore believe that crucially one size does not fit all, hence the need for individual and local engagement. The DAA is well placed with over 650 members across England to provide support with local knowledge and expertise.

We aim to engage in a ‘care-force’ working as equals in partnership aiming to deliver the best outcome for everyone. Through Health and Wellbeing boards, Clinical Commissioning Groups and Local Government we will crucially work with local GPs, primary and secondary health and social care, private and voluntary sector. Working with family carers we will support the channels of engagement and needs.

**The DAA CC2A will engage through Health & Wellbeing Boards, Clinical Commissioning Groups and Local Government Authorities**

We will provide a cohesive package of support eager to prioritise people with dementia and those that care for them.

The support will include:

• A check list to identify baselines and suggested actions plan towards achieving our shared vision.
• A template survey to use with carers to establish baseline with follow up reviews to establish consistent data (to be used to get a more national overview in a 24 month period)

• Examples of where there are services that are commissioned / provided to support people with dementia and those that care for them, especially those that promote integration

• Evidence of outcomes and the impact of services on clients for example: quality of life

• Evidence of potential savings to public services for example: Social Outcome Return Investment (SORI)

• Practical support that DAA members can provide to Health and Wellbeing Boards / CCGs to consult on type of local services to provide based on local knowledge and expertise

• A range of resources from such organisations as Carers Trust, Alzheimer’s Society, Dementia UK, Dementia Information Prescriptions, Royal College of Nursing, British Institute of Human Rights, The Information Programme for South Asian Families (IPSAF), The Life Story Network and others.

• Creative, pragmatic solutions and guidance options for example: sharing models of good practice and community infrastructure.

**OUR ACTION PLAN:**

**Engaging with Local Health and Wellbeing Boards, Clinical Commissioning Groups and Local Government Authorities:**

- Between December 2013 and March 2014 we will approach Health and Wellbeing boards (152 in England) and CCGs (211 in England) and Local Government to commit to the principles of our shared vision

**CC2A will ask: –**

- To state that ‘Yes we want to support/engage with The Carers’ Call to Action’. Evidence will be provided from within their strategy which meets the requirements of the five aims. At this stage this engagement will allow the use of the logo ‘We support The DAA Carers’ Call to Action’

**And then Health & Wellbeing Boards, Clinical Commissioning Groups and Local Government Authorities have the option to:-**

- Use the free on-line and peer support to ensure they commission and support appropriate services.
Or

• Engage with The CC2A for an in depth audit of current strategy, service provision and gaps to ensure they commission and support appropriate services (funding dependent)

AND

• To work intensively with the CC2A to turn our shared vision into reality and be modelled as exemplars between April 2014 and March 2015. (funding dependent)

The support will include:

• Audit and analysis of current provision and gaps

• Latest good practice e.g. The Triangle of Care (Carers Trust & Royal College of Nursing 2013)

• Advice on key service provision e.g. GP Dementia Information Prescriptions, CrISP

At the beginning of April 2014

A full list of Health & Wellbeing Boards, Clinical Commissioning Groups and Local Government Authorities willing to support The CC2A will be published.

By March 2015

A full list of Health & Wellbeing Boards, Clinical Commissioning Groups and Local Government Authorities achieve the CC2A recognition where they strategically demonstrate that the services they commission support carers of people with dementia. That their individual needs are assessed and are offered a range of support as well as the person they care for.

WIDER ENGAGEMENT:

A communication strategy will be developed to engage with the community at large to support The CC2A inc. Carers organisations/groups, Health and Social Care practitioners, Voluntary sector, MPs and so on and so on….

• A booklet highlighting the key issues and actions everybody can take in order to support The CC2A will be widely available throughout England by March 2014
• **CC2A** will engage with the community at large through social media twitter (@DAAcarers) and Facebook **DAA The Carers’ Call to Action** to increase awareness of the needs and rights of family carers of people with dementia.

• **Website, online resources including webinars and ‘sign up and act’ list** will be developed and managed within the DAA website [www.dementiaaction.org.uk](http://www.dementiaaction.org.uk)

**With Thanks to:**

• Uniting Carers - Dementia UK for their valuable contribution.

• Nutricia for their support through an educational grant [www.nutricia.co.uk](http://www.nutricia.co.uk)

• Tony Husband cartoonist [www.tonyhusband.co.uk](http://www.tonyhusband.co.uk) for sharing his personal experience and skill

**References:**


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)


THANK YOU TO OUR SUPPORTERS:

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