

The Carers' Call to Action



Supporting
the needs and rights
of family carers living
with dementia

Are you supporting somebody living with dementia?

Are you the spouse, partner, son, daughter, another family member or friend of somebody who has been diagnosed with dementia? Then you've probably found yourself in a caring role. You have become a "carer".

Are you having difficulty getting information or accessing expertise and support when you need it?

If so, you are not unusual.

Did you know that you have a right to information and services?

Probably not!

Well, *The Carers' Call to Action* aims to ensure that everyone who supports someone living with dementia knows their rights and is able to get the necessary level of support for both the person they care for and themselves.

The Carers' Call to Action is campaigning to achieve these objectives and bring about change for good. We are part of the Dementia Action Alliance working together with carers, people living with dementia, leading charities, public bodies and private providers across England.

You may not have the time or energy to think about campaigning for change right now – although if you do, there are some ideas on how you can help at the end of this booklet. If not, be assured that there are people who have been in similar situations to you who are doing their best to make things better. And please sign up to *The Carers' Call to Action* to show your support!



The Carers' Call to Action has created five clear aims and a 20-point checklist of what services and support should be available for people like you.

These are being taken up by organisations and individuals who are responsible for commissioning (that's the buying and providing of) services.

We hope you will be able to use our aims and checklist to see the kinds of support you could benefit from and to back up your own requests to Health and Social Services personnel for information and help.

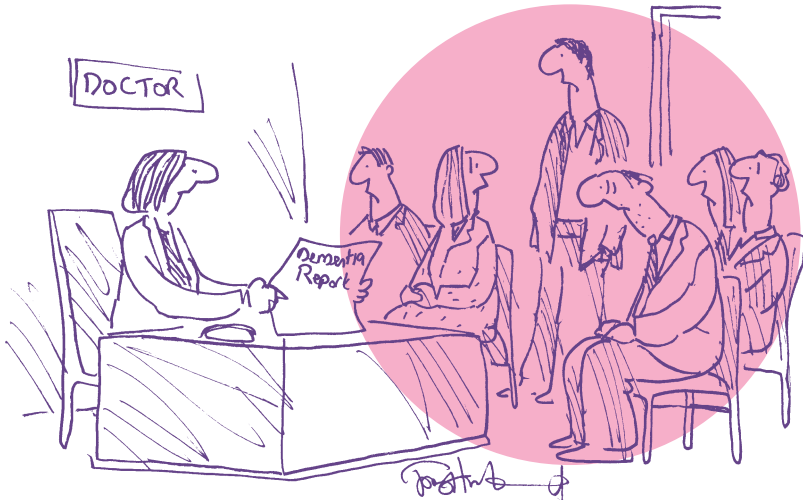


Top level support

Our call to action is based on research and endorsed by The Secretary of State for Health, The Minister for Care and The National Clinical Director for Dementia. They are all encouraging commissioning organisations to sign up to our aims and produce a better deal for carers.

The Right Honourable Jeremy Hunt MP,
Secretary of State for Health, says:

"I want to encourage you to sign up to The Carers' Call to Action. The Department of Health, Public Health England and NHS England have all signed up and together we can improve the lives of over half a million carers of people with dementia."



A diagnosis is not just given to one person



For more information email admin@carersdementiaaction.co.uk

Norman Lamb MP,

Minister of State for Care and Support, agrees:

“With one in three people aged over 65 going on to develop dementia, it is an issue which touches all of us. There are around 550,000 people in England acting as the primary carers for people with dementia, providing vital support to family members and friends. We know that carers of people with dementia experience greater strain and distress than carers of other older people. I am pleased to support The Carers' Call to Action. By achieving the shared vision, The Carers' Call to Action will have a positive impact on people with dementia and carers and improve their quality of life. I would encourage others to sign up and show their support for The Carers' Call to Action and for carers of people with dementia.”

Professor Alistair Burns,

NHS England National Clinical Director for Dementia, sums it up:

“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 and then on an on going basis.”



Who decides?

Local services and support are now decided upon and funded locally, based on your local Health & Wellbeing Board's analysis of the need for health and social care within your community.

However, this means that services across the country can vary – and vary considerably! Care for people with dementia is patchy – some areas have excellent services, some offer very little. This is also the case for carer support, especially for those who care for people living with dementia

The time is ripe. Nationally there are many positive changes taking shape, including important ones resulting from The Care Act 2014. We are already seeing more integration of health and social care plus greater community understanding of people with dementia. Now the spotlight is turning onto their carers.



The Triangle of Care



A growing need

In the UK there are 800,000 people living with dementia and the number is rising rapidly. There are an estimated 670,000 family carers of people with dementia.

Around 23 million people have a close friend or family member with dementia. So at least a third of us living in the UK are personally affected. Dementia costs the economy £23 billion a year.

It completely changes the lives of people living with this condition and those around them and we can no longer afford to ignore this growing need.

“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.”

June – wife of Bob who is living with dementia

A recent survey by Alzheimer's Society revealed that, out of 400 people, 90% felt unsupported after a diagnosis of dementia. Far too often we hear something like this from family carers:

“If only I'd known then what I know now about good dementia care, it would have made my caring for Malcolm much easier.”

Former carer Barbara Pointon MBE – wife of Malcolm, who was diagnosed with dementia at the age of 51

By working together through *The Carers' Call to Action* we can bring about real and lasting change by raising the level of practical and emotional support for carers throughout the course of their condition.



The Carers' Call to Action

– Our shared vision

We have five clear aims to improve the well-being of family carers (Our 5 R's)

1 Recognition

Family carers of people with dementia, given the character of this condition of the brain, should have their unique experience recognised.

2 Respect

Family carers of people with dementia should be treated as essential partners in care – valuing their knowledge and the support they provide, which enables the person with dementia to live well.

3 Road Map

Family carers of people with dementia should have access to a named person, with expertise in dementia care, who can give them personalised information, advice, support and co-ordination of care for the person with dementia.

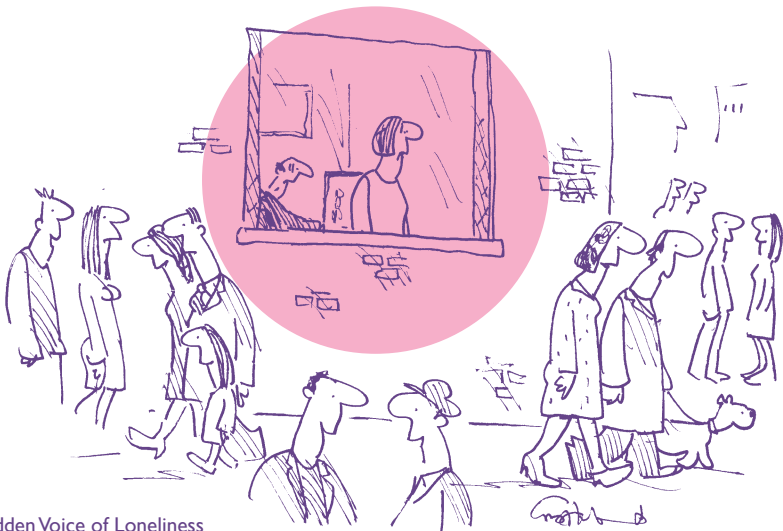


4 Regular reviews

Family carers of people with dementia should have assessments and support to identify their ongoing and changing needs in order to maintain their own health and well-being.

5 Respite

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











The Hidden Voice of Loneliness



What we want from Commissioners – Our 20 point checklist

The list below highlights the type of services and support **The Carers' Call to Action** has recommended to be commissioned by the Health & Wellbeing Boards.

It is wholly based on current research. Look to see if these services are available in your area. If not, you (or someone else on your behalf) could lobby your Health & Wellbeing Board to consider commissioning them. You can also lobby your MP and GP!

1. Pre-diagnosis support 
2. Post diagnosis information and advice 
3. Face-to-face meeting with a care expert who can give you personalised advice and support 
4. Local dementia information and resources in several formats and languages 
5. Action plan of care and support (including former carers) 
6. How to find local Carer Support Groups, including any for younger people with dementia 
7. An expert in dementia to assess your needs and those of the person you care for 
8. Referral to an expert clinician when required 



9. Support to remain socially active in your local community to combat isolation 
10. Access to appropriate respite 
11. Age-appropriate support for young onset dementia 
12. Culturally appropriate support for ethnic minorities 
13. Culturally appropriate support for same sex partners 
14. Advocacy in making decisions or dealing with legal and financial issues 
15. Dementia-trained services – e.g. dentist, nutritionist 
16. Local training for Health and Social Care professionals/paid staff 
17. Jargon buster – what services mean 
18. Local dementia awareness promotion 
19. How employers can enable carers to continue working 
20. Support for carers wanting to have a voice in improving local services. 



A full copy of the 20-point checklist can be found at dementiaaction.org.uk/carers

Definitions

Commissioners – an official person responsible for the obtaining or buying of goods and services (procurement)

Health & Wellbeing Boards – have a duty to assess the health and social care needs of the local community.

Their focus must be on joint working (integration) between health and social care involving local people in decision making.



What can you do?

– Consider your own situation

Take some time to stand back and think about your current situation. There are some questions you can ask yourself. It may then help you to seek advice locally. Or you can call any of the helplines listed in the resources section of this booklet to discuss your situation.

Make some (honest) notes below about your own situation and your feelings about supporting someone living with dementia:

Where are you now?

What's working?

What's not working?

Where are you confident?

Where would you like more information, help and reassurance?



How do you feel?

What are your feelings as a carer?

What about the feelings of the person you care for?

And the feelings of friends and family?

Where do you want to be?

How would you like your caring situation to be?

What should remain as it is?

What would you like to change or improve?



How are you going to get there?

Do you need more support?

What would be a beneficial change for you?

What would be beneficial changes for the person you care for?

What do you need to do?

What are your obstacles/challenges to getting there?

Who do you think can help you with this?



Recognise and accept that you have needs too

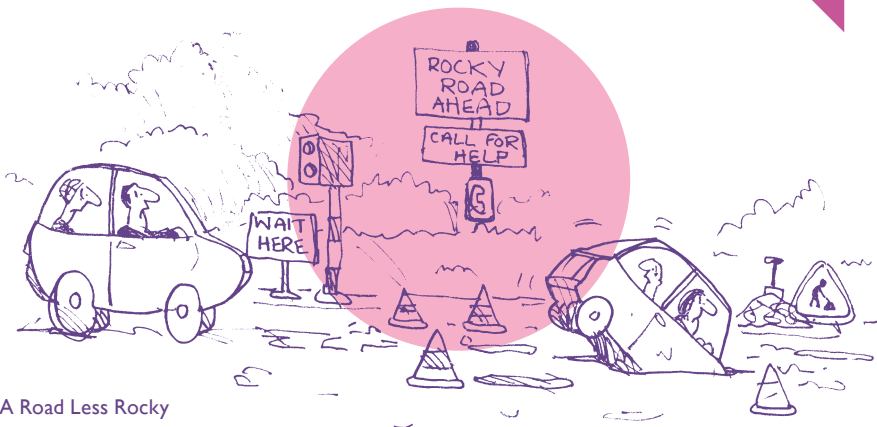
If you are caring you may tend to put your own needs last. However, appropriate, timely support and information to enable you to avoid collapse and breakdown is essential.

'A Road Less Rocky' (Carers Trust 2013) highlights good examples of where ongoing, effective support is provided but 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 learn to ask for help."



A Road Less Rocky



Get hold of Information

A Road Less Rocky – Supporting Carers of People with Dementia –
Carers Trust, London

The Triangle of Care – Carers Included:

A Guide to Best Practice for Dementia Care – Carers Trust, London

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

A Good Life with Dementia – Red & Yellow Care 2014

This is Me – a tool to support people with dementia receiving
professional care – Alzheimer's Society

The Dementia Guide – Alzheimer's Society

Your Human Rights – A Pocket Guide for Carers

British Institute of Human Rights 2012, London

Dementia – Support for Family and Friends

by Dave Pulsford and Rachel Thompson (Jessica Kingley)

And Still the Music Plays: Stories of People with Dementia

by Graham Stokes (Hawker Publications)

Building on the National Dementia Strategy: Change, progress and priorities

– All-Party Parliamentary Group on Dementia

Care Act 2014 – UK Parliament



Further information

To find out further information visit dementiaaction.org.uk/carers

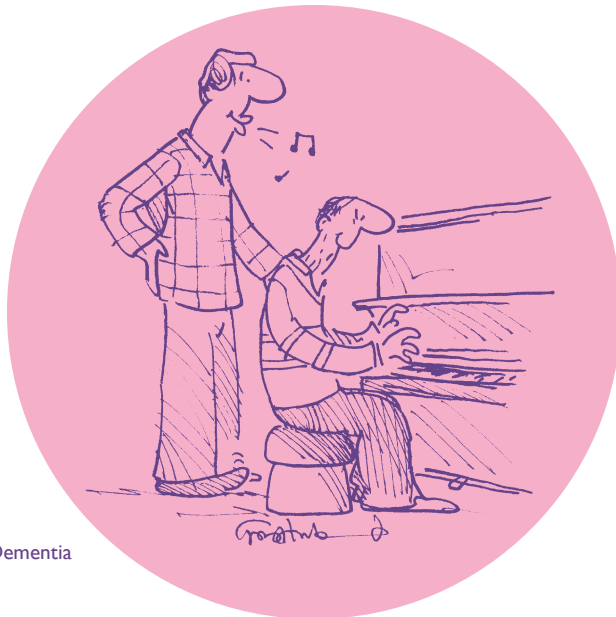
Talk to your GP about where to find Carers' Support specifically for dementia in your locality.

Call any of these Dementia Helplines to talk to somebody and/or to get further information if you are unable to get the information you need from the internet.

Admiral Nurse Direct (Dementia UK) **0845 257 9406**

Alzheimer's Society **0300 222 1122**

Dementia Web **0845 120 4048**



Living Well With Dementia



Like to do more?

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! Get in touch with *The Carers' Call to Action* team at admin@carersdementiaaction.co.uk or call the Dementia Action Alliance on **020 7423 5185**.

You could actively promote *The Carers' Call to Action* via our professional and social media networks including posting regular tweets on twitter – our hash-tag is **#DAACC2A** and our user name is **@DAACarers**.

You could write or talk to your GP, Clinical Commissioning Group, Health & Wellbeing Board, MP, Local Authority, District Council, etc. highlighting *The Carers' Call to Action* and the five aims of our shared vision. Template letters are available at: dementiaaction.org.uk/carers.

Let *The Carers' Call to Action* team know about examples of carers' support that work well in your area, including how much support you received that helped.

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 and talking to local groups.

Share your story to highlight the need for *The Carers' Call to Action*.

Commit time to speak to people, organisations and commissioners about *The Carers' Call to Action* – we can support you to do this (slides are available to download from the website).



This booklet is not intended to be a self-help guide to caring. See our website or call one of the helplines to find information suitable for you. Instead, this is a Call to Action. It's a call for you to make your voice heard – for your benefit, for the benefit of the person you care for and for all the other carers of people with dementia who are going through similar experiences to you. You may not feel up to it at the moment. But you could enlist a friend to help. And maybe in the future you will be able to take part.

The Core Steering Group of The Carers' Call for Action

DAA Dementia
Action Alliance
The Carers' Call to Action


Department
of Health

NHS
England


Supporting family carers
of people with dementia

**Alzheimer's
Society** | Leading the
fight against
dementia

Dementia UK
Improving quality of life

**Local
Government
Association**

 **dementia web**
24 hour dementia helpline
0845 1204048


carerstrust
action · help · advice


Public Health
England


Royal College
of Nursing

scie social care
institute for excellence

 **NUTRICIA**
Advanced Medical Nutrition

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Disclaimer

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admin@carersdementiaaction.co.uk

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