

# Invisible but Invaluable

Age UK campaigning with older carers

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The new force combining  
Age Concern and Help the Aged

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**Although many older carers find caring rewarding and see it as an expression of their love for the person they care for, they also tell us that they feel invisible and undervalued. Many are stressed and exhausted. They need financial, practical and emotional support.**

**This exhibition makes older carers visible and tells their stories. It asks for everyone's support, and especially that of local and national government, to make sure that they get the recognition they so richly deserve.**

British Gas has worked with Help the Aged for 11 years on a range of initiatives for people in later life and is proud to continue this work with Age UK, the new force combining Age Concern and Help the Aged. As one of the first UK companies to develop flexible employment policies to support staff with caring responsibilities; we are passionate about raising the profile of older carers, and are proud to sponsor this photographic exhibition as part of Age UK's Caring for Older Carers Campaign.



# Hello.

## **My name is Mohammed.**

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### **Mohammed Baig (64) and Ruby, his wife, care for Mr Baig's mother.**

I came from Pakistan in 1961. When my mother wanted to retire, I asked her to come from Pakistan and stay with me and the Home Office agreed. I am her only son. In our culture, sons are responsible for the parent.

My mother is partly blind and can hardly walk. She needs 24-hour care. She once switched on the gas cooker and left it on. She can't be left alone at all. Sometimes at night she removes her incontinence pad and we have to change the bed clothes and her night clothes.

In the last five years my mother has started to get dementia. Social services said they would put her into a nursing home, but I don't want her to die somewhere else. She needs people who are close to her to talk to. My mother brought me into the world and comforted me. Now she needs me. That is how it is to my mind.

Caring is a big pressure on your mind. My wife had an appointment at the hospital and I had to go with her. But we had to take mum as well and that made it difficult. We need someone, a carer, in an emergency like that.



# Hello.

## **My name is Christine.**

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### **Christine cares for her mother, Margaret.**

My dad had died. My mother had mobility problems and was getting more and more isolated and depressed. So I asked her if she wanted to come and live with me. She was 78. I thought, 'It's only for a few years.' She's 92 now!

To start with, she just lived with me and I was still working. Then in 2001 she had to have her leg amputated. Suddenly she was in a wheelchair, which changed life dramatically. I tried to carry on working until 2004, when I just keeled over one day. It took a year to get my health back.

After I stopped work our finances nosedived, so I used up all my savings. We went from having a good income to living on benefits. It certainly wounded my pride to go onto benefits. Going to the Jobcentre was totally humiliating. In the end that just played on my health.

I didn't have a life of my own. If I could have got a break, I would just have gone for a swim or something like that – be me, do what I want. When it got to crisis point they gave me four hours a week help, which is better than nothing. Carers are entitled to a life of their own.



# Hello.

## **My name is Anne.**

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### **Anne, 64, looks after her husband, Reggie.**

My husband, Reggie, had a stroke 11 years ago and now has right-side weakness. He needs help with everything – personal care, eating, getting in and out of bed – and he is incontinent.

Carers come in to get him up in the morning, but I need more hours of help from them. He goes to the day centre for three days a week. I get some time to myself and he sees other people and gets out of the house. I also have someone who sits with him for four hours a week while I go out.

My health has suffered. I have back, neck and shoulder pain that is probably from having to move him manually. I am also getting osteoarthritis in my hands and my knuckles are swollen. It's double wear and tear – from getting older and helping someone else all the time. I've been advised to rest for two months, but it's not possible.

I don't have a life of my own. I can't come and go as I choose. I have no social life.

Reggie also has vascular dementia. It's a very lonely life. I can't have a conversation with him. It's very distressing – he's a shadow of the person I've known.



# Hello.

## **My name is Leslie.**

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### **Leslie, 85, cares for his wife, Eve.**

Eve has been diagnosed with dementia. My caring changes from day to day. You are living on a knife edge – you don't know what the next hour or day will bring.

I have a nurse who gets Eve up at 7.30 in the morning and then puts her to bed at 7.30 in the evening. On Tuesday and Wednesday, Eve goes to a care home from 9.30 until 3 in the afternoon, which is a great help.

Caring is very tiring. I try to cope to the best of my ability, but I find I can't take it in my stride. Life is very stressful, especially the practical work, like cooking and housework. I can't make the meals for Eve that my mother made for me, so I feel inadequate.

I pay someone to sit in with Eve while I go to a carers' meeting on Friday. It's like opening another door. The tension goes away and my head clears. We talk among ourselves and there is a pleasant atmosphere. I find out how other carers overcome their problems. It's an escape valve. You are with people who know what you are experiencing. Without the day centre and the carers' group I couldn't manage... I don't know what I would do.



# Hello.

## **My name is Brian.**

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### **Brian, 70, looks after his wife, Madeleine.**

A lot of the help that my wife needs is with confidence-building and keeping a positive attitude. She can become very anxious and agitated. I keep an eye on her medication for epilepsy and osteoporosis. She has poor balance, a sensitivity to perfumes and food intolerances. It is sometimes very hard to relax as I keep a caring eye on things.

It is very difficult for people to understand her problems – something visible like a broken leg gets immediate sympathy. Nothing is visible to indicate my wife's problems.

I pay £31 a week for a lady to come in once a week for two hours to give me a break. I have an interest in music and play guitar and keyboard. I had a group years ago when rock 'n' roll first came on the scene, but I never gave up my day job!

I have been trying to get some financial support from the local council. It has taken four months to arrange and has been very frustrating. I had a backlog of invoices. The council wanted me to open a separate account for payments, but my bank wouldn't do it. I would prefer the invoices to go direct to the council, but they wouldn't agree to that. I can now send invoices to a third party arranged by the council for payment.



# Hello.

## **My name is Sheila.**

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### **Sheila is 75. She cares for her son Craig and for her mother and sister.**

Craig has Down's syndrome. I am also carer for my mum, who is 98 and lives in a home. I take her food, wash her clothes, wash her hair and generally look after her. I also have a sister who lives in a dementia centre. I visit and sit with her and talk to her or take her for a walk. It's quite hard work.

Craig is a full-time job. He is 37. I sort clothes out for him every day, put him in the bath then he baths himself and I get him out again. I also wash his hair. He can't be left alone in the house. Even if I just nip out to the post box, he's waiting at the window when I get back. His sight is not good so he has to link me when we go out.

Caring has got a lot harder as I've got older, possibly because I am also caring for my mum and sister now. I can't cope as well as I used to. I would like to be able to phone someone if there's an emergency, so that I can leave Craig with them while I deal with it. But it would have to be someone who had already got to know him.



# Hello.

## **My name is Lynda.**

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### **Lynda Bellingham.**

My mother, Ruth, had Alzheimer's. My father, Donald, looked after her for several years. They were both in their seventies. He was a farmer but he had an accident and went from being a very fit to not so fit older man. He found it very difficult to cope. We tried to find some respite for her. Unfortunately, she went into one home where she fell and broke her hip so she then became completely immobile. The whole situation then quickly degenerated.

Dementia care is such a different form of caring. You have to make the person feel secure. The paid carers did their best but they were practical people and would ask mum questions and that panicked her.

The emotional strain on my father was immense. It's not like seeing anything getting any better. My sister bore the brunt of the caring. I would go down for a week to give my sister a break and solely concentrate on my mother. A week is nothing but it made me conscious of how important respite is.

When mum went in the home dad was heartbroken. Again I would go down for a week to be with him. We would go over old times. It was important for my father to have those memories and talk to somebody because you lose your sense of identity when you are a carer. I consider it an honour to represent the 'invisible'.

**You recognise me, now recognise them.**

# Make carers visible.

## **Support us.**

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### **We want the government to:**

- Introduce a Carer's Allowance for pensioners.
- Simplify applying for Carer's Allowance and related benefits.
- Give us a statutory entitlement to the support we need to have a good quality of life, to protect our health and to reduce our isolation.
- Honour funding already agreed and ensure it is really used to support us.

### **We want the NHS and health professionals to:**

- Let us know that we can register as carers with our GP and have regular health checks.
- Consult us and respect our views.
- Find a way to identify 'hidden' carers and provide them with information and support.

### **We want local authorities to:**

- Make us aware that we have an entitlement to have our needs assessed.
- Ensure that we have a choice of appropriate, flexible and good quality services to meet the needs of both the person we care for and ourselves.
- Help us to get together to support one another.
- Consult us about services.

# Make carers visible. **Get in touch.**

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**If you would like more information about this campaign and how you can support it, go to [www.ageuk.org.uk/oldercarers](http://www.ageuk.org.uk/oldercarers) or telephone 020 8765 7626.**

If you are an older carer, please complete one of the cards which are available at the exhibition and tell us about your experience of caring and what help you receive or need, or ring 020 8765 7626 and one will be sent to you.



# Thank you. **All of you.**

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Age UK would like to thank carers from Birmingham, Oxfordshire, Waltham Forest, and from Morley and Crossgates in Leeds, and the hundreds of other carers who wrote to us to share their experiences of caring and tell us of the help they receive or need.

Age UK is working locally and in partnership with Age Concerns.

Photography by Sam Mellish.

