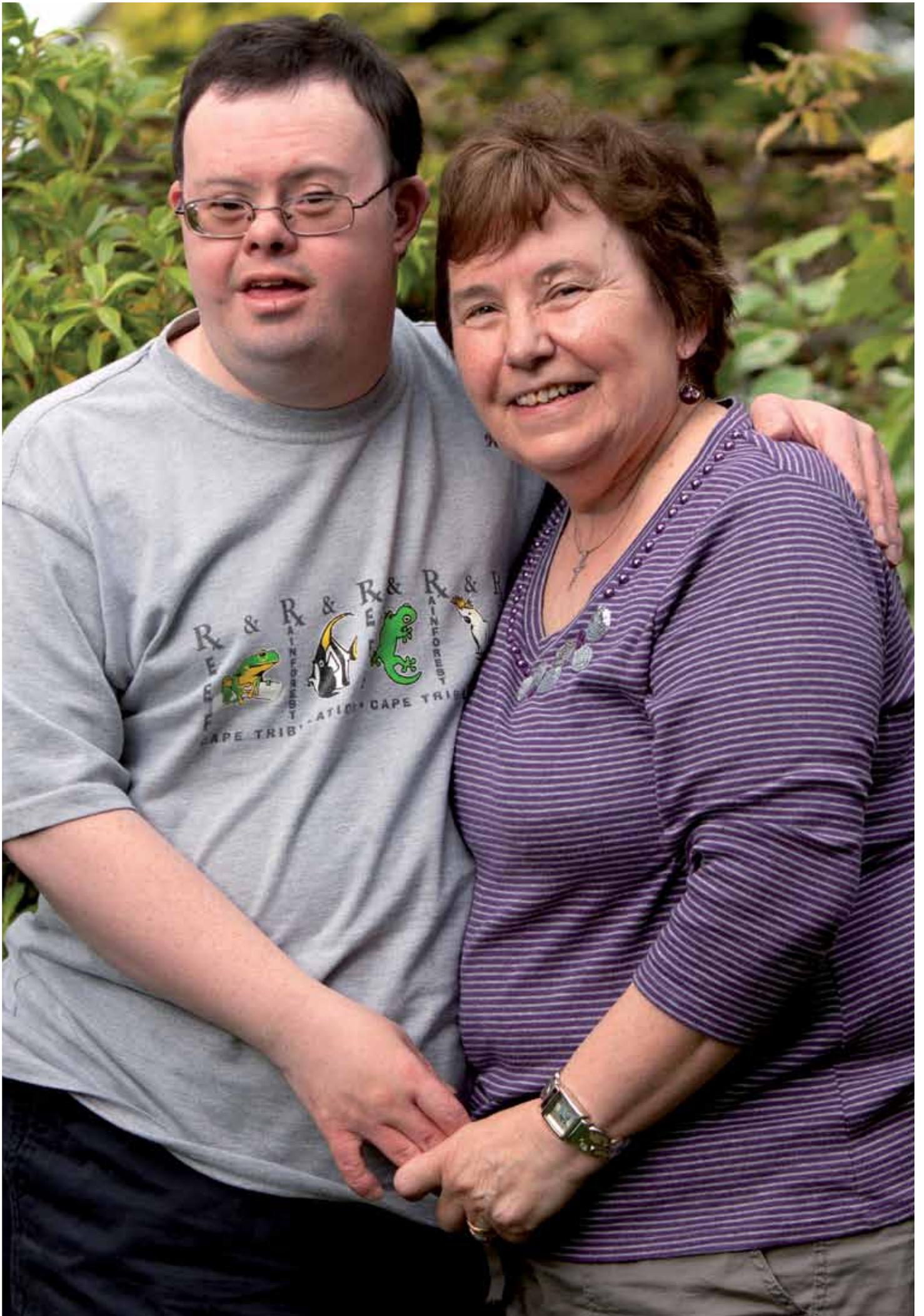


Invisible but Invaluable

Campaigning for greater
support for older carers





Contents

Introduction	2
Summary	4
‘We never retire’	6
Support for older carers	8
Financial support – Carer’s Allowance	8
Support to have a life and identity of their own – the importance of respite	10
Stress and ill health	11
Social isolation	13
The benefits of respite	13
Day centres and older carers’ support groups	14
Care reform, direct payment and service provision	16
Support from professionals	17
Training paid carers	20
Getting information to older carers	20
Carers’ stories – What it is like to be a carer post-retirement	22

Introduction

Care and support is currently in crisis due to lack of funding. Fewer and fewer older people are qualifying for local authority support. There are few services that are aimed at preventing those with low-level care needs from reaching a crisis situation. Funding cuts threaten to turn this problem into a disaster.

Research commissioned by Age UK estimates that a cut of 13 per cent over two years would lead to an additional 490,000 people who have care and support needs losing their entitlement to local authority help. In the longer term, rising numbers of older people will lead to increased demand for care and support.

Support for the person needing care is often heavily supplemented by informal carers, usually a relative. When cuts take place, informal carers are forced to work harder, often sacrificing their own health and well-being and their own activity and identity as an independent person. Older carers, especially, need more support, not less, as many of them experience declining health exacerbated by caring.

In recent years, Age UK has held listening events with people in later life to discuss pension reform and care reform. At many of these meetings we met older informal carers – people over retirement age who were looking after a husband, wife or partner or for an adult disabled son or daughter. Although many found caring rewarding and an expression of their relationship with the cared-for person, they also told us that they felt invisible and undervalued. Many were stressed and exhausted.

OLDER CARERS NEED URGENT ACTION. THEY NEED FINANCIAL, PRACTICAL AND EMOTIONAL SUPPORT.

Older carers often receive no financial support, or only do so after going through a very complicated system. They tend not to refer to themselves as carers, as they are looking after family members, and therefore they may be difficult for professionals, who might offer help, to identify.

Now that care reform is on the agenda, there is an opportunity for the Government to show in practice that it values older carers.

Older carers need urgent action. They need financial, practical and emotional support. They save the Government and society generally around £15 billion. Funding to support them should not be cut.

The previous Government's National Strategy for Carers pledged that by 2018 carers would be supported so that they are not forced into financial hardship by their caring role. This is too long a time-frame for older carers.

The current Government has established a Care Commission and has said that it will publish a 're-focused Carers' Strategy' in April 2011 and plans to 'improve access to respite care by using direct payments to carers and better community-based provision'.

Demographic change and an emphasis on care in the community will mean greater numbers of older people caring for other older people. It is important that policy-makers get their policy for carers right.

This report is based on correspondence and discussions with older carers. Along with a photo exhibition touring the country, it seeks to make older carers visible. We want the Government to ensure that support for older carers is specifically included in future care reform.

There are two distinct groups among older carers – those who are long-term carers for a disabled son or daughter, and those who have undertaken caring in later life, usually for a husband, wife or partner, but sometimes for a mother or father. The two groups face some similar challenges, such as the impact of caring on their health. They also face some different ones. For example, those who have cared for 40 years for their disabled son or daughter tend to have found their way through the system, although they can still find getting support trying as circumstances change. Both groups have contributed to this report.

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 to tell us of the help they receive or need.

Summary

The older carers, who spoke about their experiences for this report, are very committed to looking after their family member or friend. They take pride in enabling the cared-for person to remain in familiar, comfortable surroundings and to be looked after by someone who really cares.

However, the carers themselves pay a heavy price for their dedication. Many experience high levels of stress and anxiety, as well as general health problems. They are often lonely and socially isolated. The lack of financial support, since Carer's Allowance is not paid post-retirement, and the restricted availability of respite care were crucial issues for them. They also wanted to be treated with respect and to be consulted by professionals. They need reliable and properly trained, paid carers.

There are many ways in which they could be better supported.

We want the Government to:

- Simplify the application process for Carer's Allowance and related benefits.
- Introduce a carer's allowance post-retirement.
- Give carers a statutory entitlement to the support they need in order to achieve an acceptable quality of life, in terms of mental and physical health, and opportunities for social and financial inclusion.
- Ensure that funding already agreed is honoured and used for the purpose for which it was intended. Resources should be transferred from protected NHS spending if necessary. As soon as the economic situation improves, funding should be increased. Cutting support for carers is inhumane and counter-productive.

We want the NHS and health professionals to:

- Target carers to register as carers with their GP and have regular health checks.
- Respect carers' views.
- Consider how they can identify carers and provide them with information and support.

We want local authorities to:

- Make carers aware of their entitlement to have their needs assessed.
- Ensure that people have a choice of appropriate, flexible and good-quality services to meet the needs of both the cared-for person and their carer, including the opportunity for carers to get together to support one another.
- Promote their services and provide accessible information and advice to older carers.
- Avoid a reduction in local eligibility for care services, where this will increase the burden on carers.
- Put a clear framework in place to give older carers greater influence individually and collectively in local authority decision-making. They should be offered support to enable them to participate.

Fact file

- In 2001, around 6 million people provided unpaid care in the UK.¹
- Three million of those are aged over 50 and older, and they provide more than £15 billion in care each year.
- In England in 2010, there are 959,836 people aged 65+ providing unpaid care to a partner, family member, or other person. These include 634,680 carers aged 65–74; 277,274 carers aged 75–84; and 47,882 carers aged 85 and over.²
- A quarter of all carers aged 75+ provide 50 or more hours of informal care each week.³
- Older carers differ from younger carers in that they care for shorter periods; are more likely to provide intimate personal care and heavy nursing tasks associated with terminal care; and to be caring for a husband, wife or partner.⁴
- Older carers represent a sub-group of carers with special needs that are not necessarily met by present service provision.⁵

1 See Office for National Statistics website: www.statistics.gov.uk/ci/nugget.asp?id=1336

2 Projecting Older People Population Information System (POPP) website, Department of Health. Available at: <http://www.poppi.org.uk/index.php>

3 *Family Resources Survey 2007/8*, Department of Work and Pensions, 2009.

4 Julie McGarry and Antony Arthur (2001), 'Informal Caring in Later Life: A Qualitative Study of the Experiences of Older Carers', *Journal of Advanced Nursing* 33(2): 182–9. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/jan.2001.33.issue-2/issuetoc>

5 See note 4.

‘We never retire’

For most of us, retirement is seen as a time to relax, spend time with family and friends and pursue interests that we didn’t have time for when we were younger or in employment. However, almost a million older people spend much of their retirement caring for others.

‘We never retire. As you get older, if you didn’t have your son or daughter, you’d be doing all sorts of things. But your brain is working for two people all the time.’

Audrey, 71

‘I get up at 7 every morning. It would be good to do what a retired person would do and not have to worry about all the washing and ironing – even just for a weekend.’

Shirley, 71

‘We are both disappointed that life has not turned out as we expected when I retired.’

Brian, 70

Caring is not only about keeping up morale, keeping someone company and encouraging them; it is also frequently about doing all of the cooking, cleaning, personal care, lifting and much more for the cared-for person. All this is done by people who are often experiencing poor health or the effects of growing older themselves.

‘Get more stressed and slower. Can’t do things as quickly. You have to take care as you go downstairs. Can’t lift things. Can’t cope mentally.’

‘It’s stressful. As the son or daughter you care for gets older, there are age-related illnesses, mental problems. Things that they used to do before, you have to do for them or help them to do. So you are not getting the rest that you should get when you get older. And you have health problems probably accelerated by the caring. Your joints start aching more. Perhaps they wouldn’t if you could rest.’

Pat, 62

Older carers need support to care, but also to ensure that they have a good quality of life themselves and can rest and care for their health.

OLDER CARERS NEED TO ENSURE THAT THEY CAN REST AND CARE FOR THEIR HEALTH.



Support for older carers

Financial support – Carer’s Allowance

Carer’s Allowance does not have an upper age limit but overlaps with the State Pension. That is, it is not paid in addition to the pension, creating a great sense of injustice among carers. They feel that it is unfair because they have no recognition of their caring or help towards the costs. Some received Carer’s Allowance before they reached State Pension age, which then stopped when they got their pension. Older carers complain that they are still caring and cannot see why Carer’s Allowance is no longer paid. This influences their view that they are undervalued and ignored.

‘Carer’s Allowance should be paid after retirement.’

Gill

‘It would be good if Carer’s Allowance were paid after retirement, but it would not have to count for assessment otherwise it would be taken away again.’

Anne

‘I am disabled (in receipt of Disability Living Allowance). I retired at 57 on medical grounds and my 69-year-old husband cares for me. I know he gets very down because my mobility is poor, and he is trying to sort out a bungalow we bought, so he is exhausted all the time. Before, we shared all the household tasks but I am in the position of watching someone I love work themselves into the ground. My husband does not receive Carer’s Allowance. My 92-year-old father-in-law is a carer to his wife who is 85. He does not receive any Carer’s Allowance for this either. We have all paid our way and now we need a little help.’

Lynn, 63

‘I have worked full time all my life. My Carer’s Allowance was withdrawn when I retired. I still do the same amount of caring, if not more, now that I am 70.’

Christine

Despite not actually being able to receive Carer’s Allowance, those on a low income can still benefit from claiming it because it can increase the level of means-tested benefits, such as the carer’s premium in Pension Credit. This is important extra money for those on a low income. The extension of Carer’s Allowance in 2002 to the over-65s led to over 250,000 carers being entitled to the additional amount for carers in Pension Credit. However, this is a very confusing system. In effect, people have to claim a benefit they cannot be paid, in order to get a higher rate of a different benefit.

Issues relating to financial support for older carers have frequently been discussed in Parliament. The Public Accounts Committee of the House of Commons report on carers in 2009, *Supporting Carers to Care*, said that one in five carers who receive benefits have problems with the application process. It recommended that those older carers only eligible for top-up payments should be able to apply for them directly and that communication and the application process should be simplified.

The Work and Pensions Committee report of 2008, *Valuing and Supporting Carers*, recommended replacing Carer's Allowance with two benefits:

- An income replacement benefit to be called Carer's Support Allowance that would not be paid to pensioners.
- A caring costs payment, paid to pensioners, that would compensate carers for the extra costs of caring and that would allow them to buy in some help. The committee recommended setting this at between £20 and £50 a week.

Although the previous Government's review of the carers' strategy accepted that there were problems with carers' benefits, no changes were announced and reform was put off.

There is significant public sympathy for financial support for carers. Research for the Department for Work and Pensions by Ipsos Mori showed that 88 per cent of people think that carers should be paid more than they are currently paid and should have more access to respite care.

It is time that this injustice was corrected. Older carers need a post-retirement carer's allowance. They have to pay for many of the services they need. Paying them an allowance as a carer recognises the enormous contribution that they make and would go a small way towards enabling them to maintain their own health and well-being. Older carers also want the application process for carers' benefits to be simplified.

We are calling on the Government to:

- simplify application procedures for Carer's Allowance and related benefits
- introduce a carer's allowance post-retirement.

Support to have a life and identity of their own – the importance of respite

Carers experience a wide range of challenges. They say they feel exhausted and frustrated. Exhausted because they have so much to do and often have interrupted sleep as a result of their caring. Frustrated because of their isolation, their lack of a social life and their difficulty in simply leaving the house, as they can't leave the person they care for alone.

Those carers whose cared-for person has dementia or Alzheimer's also have difficulty in coping with challenging behaviour, the constant misplacing or damaging of personal and household items, and the loss of their company and conversation.

'Expect spouse to be normal and they are not. It is a source of frustration.'

'Very stressful. I'm walking on eggshells. It's easy to say the wrong thing.'

They also express a sense of loss of their own identity because they are so focused on their caring role and the cared-for person.

'Haven't got a life. Can't look to future. Can't plan ahead.'

'I think the main thing is that I don't have a life of my own, having to care for someone else all the time. 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. You can't have a conversation with the person you are caring for. It's very distressing – he's a shadow of the person I've known.'

Anne, 64

Yet carers have their own interests or friends they would like to meet up with, or simply need to rest. It is important to recognise the individuality of older carers and their need to continue activities and interests which can help to maintain their identity, mental health and sense of well-being.

'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 the day job! I am also secretary of a local club and do the minutes and future agendas.'

Brian, 70

Stress and ill health

Many carers experience stress. They often had a division of labour with their husband, wife or partner and now found themselves not only delivering personal care but trying to keep up with the jobs that both of them used to share – cleaning and maintaining the home and garden, doing the shopping, washing and ironing, DIY, etc.

‘Getting meals, washing, ironing, snatching a few hours to shop – it’s a lot!’

Some, especially those looking after someone with dementia or Alzheimer’s, also found coping with difficult behaviour very hard. The person they cared for might constantly cause them work and anxiety.

‘The kettle leaked but my husband continued to use it even though it was dangerous. I had to break it up.’

‘Last week he took the vacuum cleaner to pieces and cut the flex. He said a man had done it. He throws clean clothes on the floor and gets dirty ones out of the laundry basket.’

‘I spend hours looking for lost things – hearing aid, clothes, specs...’

Older carers are often so committed and focused on caring for their loved one that they frequently neglect their own health. At the same time, their caring role may undermine their health. They find it difficult to take time out to care for themselves, even when they are sick.

‘Things happen to me that I ignore – it’s difficult to change focus on to myself. My focus is so much on the person I care for. My health has suffered. Stress from caring is one of the main causes. 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.’

Anne, 64

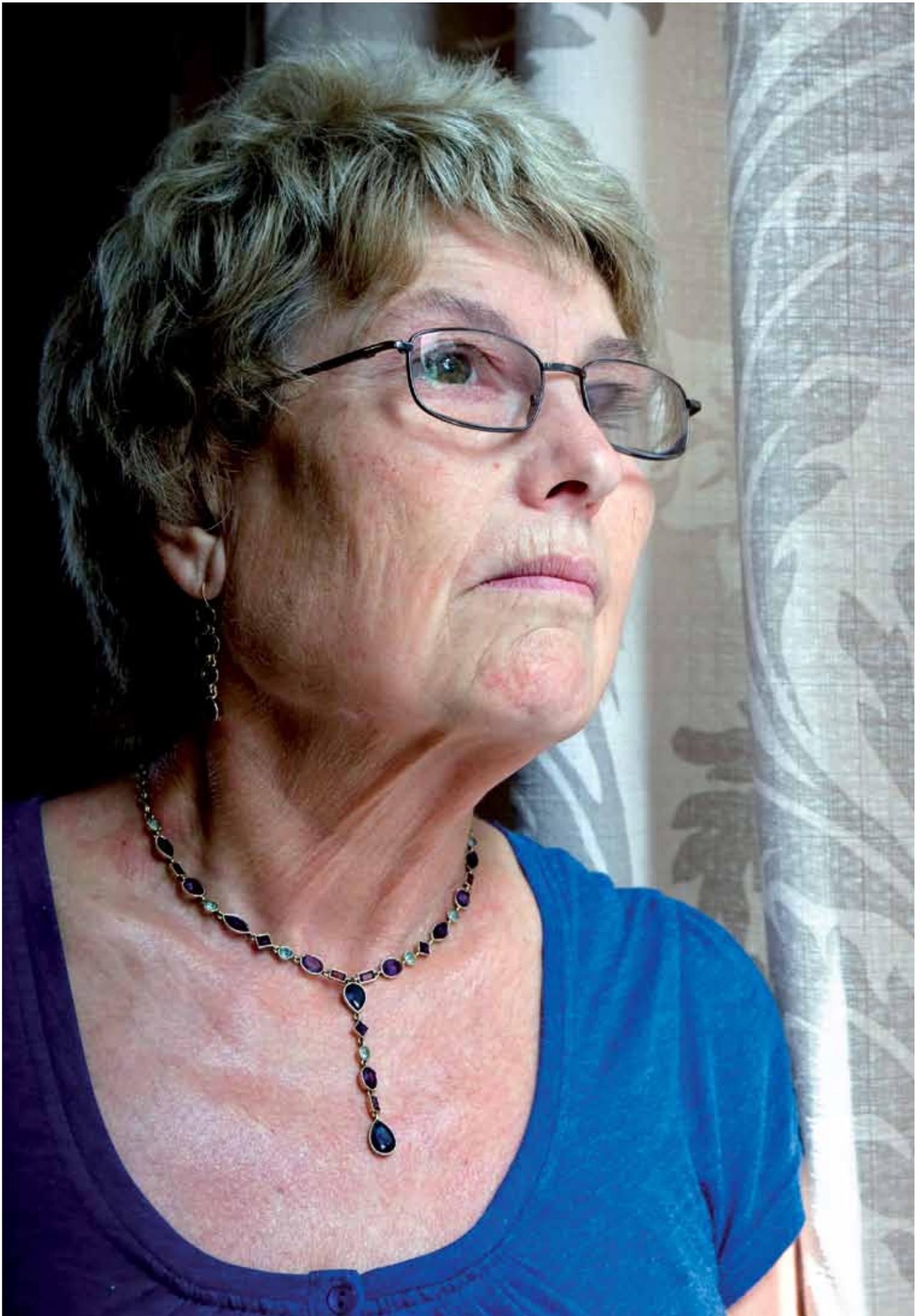
‘I have a congenital heart condition which is under control and my eyesight is not very good but you don’t think about yourself very much when you are a carer.’

Iris

‘It would be a complete luxury if you had a bad cold to be able to lie down or go to bed. As a lone parent, I have never been able to go to bed when I have been ill.’

Susan

Older carers should not have to sacrifice their health. Maintaining the level of care for the cared-for person also means maintaining the carer’s health. The NHS should encourage older carers to register as carers with their GP and to have regular health checks. The GP, as well as being vigilant about the carer’s health, would also be able to offer home visits knowing that it is difficult for the carer to leave the home.



Social isolation

Older carers' difficulty in leaving the house, compounded in some cases by their former friends, discomfort with the condition of the person they care for, can lead to social isolation.

'People don't ring us like they used to. It's like a bereavement, but social life is important.'

'Our circle of friends is getting smaller – people feel awkward, but also there is the fear or stigma of mental health conditions.'

'It's difficult asking people to sit with my husband because he can't communicate. Those I expected to help have taken a step back.'

The benefits of respite

Access to respite can play a central role in protecting the health and well-being of older carers and maintain some life of their own, but it is in short supply. Respite may be for the cared-for person to stay in a residential facility, giving the carer a break in their own home or the opportunity to have a short break away. It may be planned, regular respite to enable carers to have a few hours to themselves or emergency respite when the carer is ill. In some cases, carers need emergency respite to take care of the person they usually care for while they attend to another relative who suddenly needs their help.

'YOUR FRIENDS START DROPPING YOU BECAUSE YOU CAN'T GET OUT OR THEY DON'T WANT TO COME ROUND TO YOU. SO THE CARER BECOMES MORE ISOLATED TOO.'

Christine

'You need someone who you can phone up in an emergency. For instance, I have a husband who is not very well. Somebody you know will come to sit with them. Someone you get to know.'

Sheila, who cares for her disabled son

'It is very hard. It 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 quite difficult. We need someone, a carer, in an emergency like that.'

Mohammed, who cares for his mother

Many carers are finding that the little respite they have had is being cut.

'I get respite care, which is my lifeline, but from next year that is being reduced by four weeks.'

Grace, whose husband has advanced Parkinson's disease

'My daughter gets 23 nights per year respite, for which we are grateful. Last year, we had to fight to retain 23 nights – it was suggested that we halved it. My husband battled with the local authority to hold on to it with the help of a supportive GP.'

Christine and her husband, both in their 70s, care for their disabled daughter, aged 46

According to the Princess Royal Trust for Carers and Crossroads Care, of the £100 million the last Government committed through the NHS to provide support for carers in 2010–11, only 26 per cent is planned to be spent by primary care trusts to increase support for carers. Approximately one-quarter of primary care trusts in England are planning to reduce spending on carers' services.

Cutting funding for support for carers is inhumane and counter-productive. Funding already agreed should be honoured and used for the purpose for which it was intended. As soon as the economic situation improves, it should be increased.

Day centres and older carers' support groups

Two of the services which older carers particularly rely on and appreciate are day centres and older carers' support groups. They feel that day centres offer something to both themselves and the cared-for person. The cared-for person can have an opportunity to mix with others, have a change of environment and participate in activities. In their absence, carers can get on with housework or other tasks or relax or go out, without having to be constantly vigilant and anxious about the person they care for. However, they are afraid of future cuts to these essential services. Some have already experienced closure of a centre and the distress it had caused to the person they cared for.

'On Tuesday and Wednesday, Eve goes to a care home from 9.30 until 3 in the afternoon, which is a great help. They have games and entertainment. I can get down to my jobs while Eve is away.'

Leslie

'It's good that 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. He had to move from his previous day centre when it was closed. That really distressed him as he lost familiar surroundings. The current day centre is overcrowded and they are talking about extending, yet a purpose-built building was closed down. It was very upsetting for everyone who was forced to move.'

Anne

'Darryl goes gardening and there's a coffee shop. I would want more staff so that they can go out more.'

Jean

A member of Morley older carers' group, whose members care for adult disabled sons and daughters, explained:

'Our main concern at the moment is that they are going to be closing the centres that our sons and daughters go to during the day. I have two disabled sons – the eldest is 43 and the youngest is 35. We haven't heard anything clear about this. We can see, knowing how things happen, that we are going to have them at home more. But we rely on them being out every day between 9 and 4 as a time for us to do what we want. If the centre is taken away, it will only heap more caring on to us.'

'We (carers) are the last people to be considered when they are considering anything.'

'We don't want them at home all day because they are not mixing. They don't want to be stuck at home.'

Elsie

Carers' groups are a source of mutual support and information. Carers enjoyed being with people like themselves and developed bonds with the group.

'Talk to people in the know'.

'This is my relief – absolutely tremendous.'

'It's like a little holiday, a relief valve.'

A minority of carers have access to other services, such as an art course.

'To continue the availability of activities, such as art courses for the carer and cared-for person and fund them. It takes you out of yourself.'

Others have attended 'Caring with Confidence', a course run by Age UK Oxfordshire.

All of these services have uncertain funding in the future. Yet when asked what they would do in the event of closure, most carers cannot even contemplate the impact on them and the person they care for. Given the enormous strains that carers are under and the need to support them to have a life of their own, careful consideration should be given to the impact on carers before any curtailing of services.

Care reform, direct payments and service provision

An important part of care reform is 'self-directed support', which enables people to manage and control their own services. This can be achieved by people purchasing their own care using a direct payment provided by the local authority. Not everyone wants to do this and 'Personal Budgets' are meant to give people a choice. If a person qualifies for local authority care, they can have a choice of a cash payment, have the local authority arrange support for them, or a 'middle way', such as a 'notional budget' where the local authority arranges the services.

Direct payments are seen as a positive step by many older carers.

'I have someone to get him into bed at night. It's been better since I have had direct payments as I hire the carers myself.'

Anne

Others see them as an added burden and a big responsibility for the carer on top of everything else, as Brian's story (page 27) shows. Considering how little help Brian was asking for, the process of accessing payment was enormously time-consuming and frustrating.

'Personalisation' is also meant to encourage more competitive markets for care services. However, people may find there is no choice of local services to buy with their direct payments.

Personalisation should not lead to greater social isolation for the carer and the cared-for person. Carers should have the opportunity to get together to support one another. Local authorities should ensure that people have a choice of appropriate, flexible and good-quality services, to meet the needs of both the cared-for person and their carer.

Older carers need greater influence individually and collectively in local authority decision-making. A clear framework and support to enable them to participate is important.

Support from professionals

In the course of their caring, older carers inevitably came into contact with a range of professionals. The attitude of professionals towards them and the person they cared for is very important in both ensuring that the cared-for person receives the help they need but also to the carers' levels of frustration and stress, and sense of their own worth.

Many speak highly of the professionals that they find supportive.

'Our GP is very supportive and we have a care manager who has helped to put things into place. Occupational therapists have also been very supportive, providing us with essential equipment.'

Josie

Implementation of the 1995 Carers Act introduced a requirement for local authorities to address the needs of informal carers in care planning, but implementation has been variable. Local authorities should make carers aware of their entitlement to assessment.

'I've had difficulty getting care manager/assessment to enable respite care.'

'Professionals should listen and return phone calls. Care assessments should not be filed on the line manager's desk then vanish.'

Elaine

'It is really slow getting help and equipment you need from social services.'

Bernard

'I would like more involvement from the psychiatric health team in assessing and advising as dementia progresses.'

Jackie

'More contact with dementia care nurse would be appreciated – not every 15 months or so, as at the moment.'

Harold

'You need someone allocated to you who you can sound off to like a social worker. Someone you can have a meeting with every so often who will listen to you when nobody else seems to listen to you. Like to talk to them tell them how you are feeling – things you can't tell your family. Because everybody sees you as jolly and happy but sometimes you are not.'

Susan

'We just feel like we have been forgotten.'

Older carers find carer's assessment forms very complex. There often has to be a crisis before any intervention, whereas an intervention to avert an impending crisis would be more productive.

Carers want their role to be recognised by professionals. They need contact with professionals for reassurance that they are doing the right thing – a named person they can talk to, who would get to know them and the person they look after. They also need continuity in the support they received.

'I think one of the things that set us back was that, quite a few years ago, we weren't allocated social workers. When the children were younger, if you had any problems or wanted respite, you had an allocated social worker who knew you. All of sudden it stopped. If ever, for some reason, like if you think tablets are causing side effects, there is no contact, no one to talk to. I've waited about nine months just to get a social worker to come to see me so that I could get my son's name down for independent living. That is wrong.'

'They don't know you and you don't know them. We found that one of the worst things that's happened. All of a sudden you are having to tell your story again.'

Some carers are frustrated and angry because of insensitivity of some professionals and their lack of interest in the views of carers.

'They ignore carers. If they had bothered to talk to me, it might have made a difference for my mother. They only talk to the service user. For example, I've thrown my hands in the air when they asked her, "Can you cook for yourself?" She would say "Yes", but for her it means putting a meal in the microwave. If they had asked, "Did you cook your meal last night?" she would have said, "No, my daughter did". It's how the questions are asked.'



Training paid carers

Older carers have a similar mix of positive and negative experiences of paid carers provided to support their cared-for person and their own caring role. While some have been a source of support, almost like a family friend, others have been unreliable, unmotivated or untrained for the role.

'It is sheer, relentless stress that is the main problem for the carer. Regular support from trained, trustworthy and sympathetic carers is the primary help for the main carer.'

Bill

'You can improve any system, even if it is already good. Social services provide 28 hours per week of help from carers and five hours' respite break. This is a big help. Although sometimes the carers are late or don't turn up at all.'

Mohammed

*'I have to train the carers myself as the company doesn't train them to the level needed to care for someone with such complex needs. We need more carers who understand PEG feeding.'*⁶

Iris

Caring should be treated as a profession. Care staff should be better trained and be better paid. Local authorities should ensure that the services they commission deliver to a high standard. A bank of carers trained to an adequate level is needed to support those caring for people with more complex needs.

Getting information to older carers

Many carers have been or are unclear about what services are available, how to access services or who to contact about existing services. Information about benefits and entitlements can be hard to find and they find much information confusing. Carers need information, especially about how direct payments and personal budgets work.

'Nobody tells you anything. It's almost like a secret society. You have to find out. When mum needed a wheelchair and stair lift she went to the council and they said "Well, it's going to be three years". So she paid for her own. When you make the house suitable for someone with disability, no one tells you that you are entitled to a council tax reduction. That would have saved us a fortune. I only found out when it was too late to claim back for all the years I'd paid the extra.'

Christine

⁶ Percutaneous endoscopic gastrostomy: a means of feeding using a tube that passes through the abdominal wall directly into the stomach, so that nutrition can be provided without swallowing.

‘We should be able to go to a one-stop shop and get all the information we need there. There are so many older people in the country. They should be able to ring up about their problems and talk it through and get a proper answer so that everything fits together. There are a lot of hidden older carers and no one is doing anything about trying to find them. Help needs to be advertised. The ones I’ve come across who have been hidden only get help when there’s a crisis. There is some knowledge but not enough, and things change. When you are older especially, the older person you care for often changes for the worse and that’s when there’s a crisis.’

Gill

As well as the need for more information about what is available, many carers feel they need support, help and guidance to access services and benefits. Independent, good-quality information, advice and advocacy should be available to carers wherever they live.

‘Drop-in centres for refreshments and much-needed advice. We need more of these places as the nation of pensioners gets larger.’

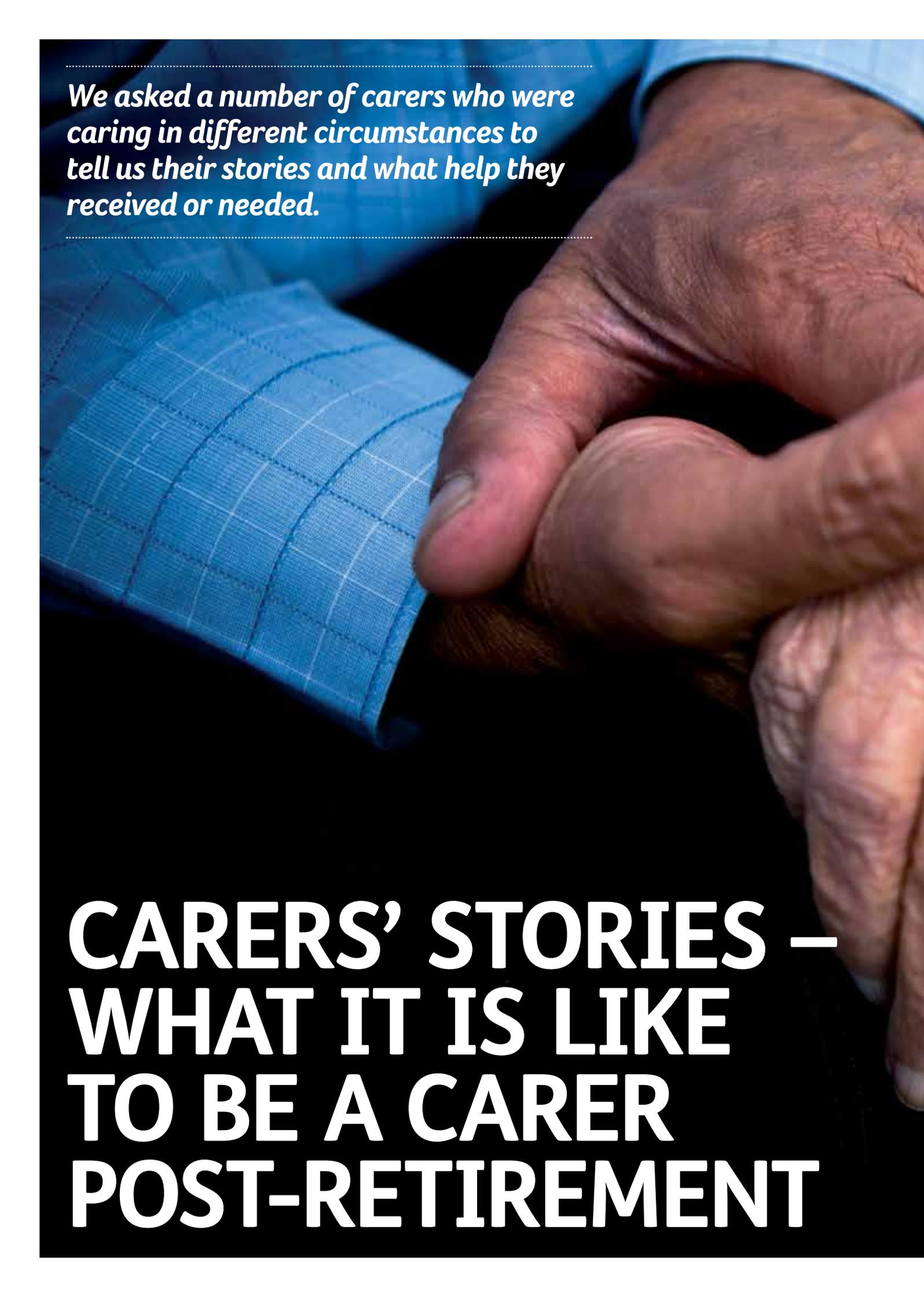
Jean

Professionals were seen as potential allies in accessing information.

‘We need more education for professionals. We did some research into carers’ needs for “Back me up” (a Carers UK campaign) in Birmingham. Because of the advertising about that and the offer of emergency care, the number of hidden carers who have come forward is unbelievable. We fought to get information about the carers’ emergency response service on the bottom of the assessment form and they tick it. Surely, if social workers and district nurses knew about carers’ groups and other information, they could give out information to people who need help and support.’

Gill (Chair of Carers UK Birmingham branch)

GPs and other health professionals also have an important role to play. Health checks, such as that for over-75s, could provide a means to identify older carers who are not known to care providers. Nurses can take a lead role in working with this group by identifying older carers; developing strategies to assist them in their caring role; and by responding quickly to crises that can develop among this group.



We asked a number of carers who were caring in different circumstances to tell us their stories and what help they received or needed.

CARERS' STORIES – WHAT IT IS LIKE TO BE A CARER POST-RETIREMENT



ANNE

Anne, 64, looks after her husband, Reggie.

My husband, Reggie, worked as a doctor and I was a nurse. Reggie had a stroke 11 years ago. He now has right-side weakness and needs to be looked after full-time. He needs help with everything – personal care, eating, getting in and out of bed – and he is incontinent. Sometimes I have to get up two or three times a night.

Carers come in to get him up in the morning. There should be two carers at the same time, but they might be late or sick and I end up helping the person who does come. I need more hours of help from carers.

It's good that 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 'Take a Break' for four hours a week where someone comes and sits with him while I take the dogs for a walk or just 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. You tend to put the other person first. You can't be sick yourself.

I think the main thing is that 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. You can't have a conversation with the person you are caring for. It's very distressing – he's a shadow of the person I've known.





BRIAN





Brian is 70 and looks after his wife, Madeleine.

My wife's need to be cared for has developed gradually over time from three or four years ago. A lot of the help that she needs is with confidence-building and trying to keep a positive attitude on things. She can become very anxious and agitated. Because she has osteoporosis, my wife cannot lift or carry heavy things such as shopping. I have torn tendons in my shoulders, which makes lifting things difficult, and I am diabetic.

I keep an eye on my wife's medication for epilepsy and osteoporosis. She has to be careful when walking out, as loss of hearing in one ear has caused a loss of balance. She also has a sensitivity to perfumes and has to be vigilant about what she can eat due to gluten, wheat and additives intolerances. It is sometimes very hard to relax properly in the day as I keep a caring eye on things.

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

We pay a lady to do a couple of hours of cleaning each week and similarly, in season, a gardener. Angela, a lady from the local Age UK, comes in once a week for two hours which gives 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 for months to get some financial support from the local council. I pay £31 for two hours for someone to sit in with Madeleine. The financial help from the council took a long time to arrange. Consequently, I had a backlog of invoices. The council wanted me to open a separate account for payments but my bank said it was not in their terms and conditions. I would prefer the invoices to go direct to the council, but they wouldn't agree to that. This went on for four months and was very frustrating for me. The situation has at long last been sorted out and I can send invoices to a third party arranged by the council for payment.

MOHAMMED

Mohammed Baig, 64, and Ruby, his wife, care for Mr Baig's mother.

I came from Pakistan in 1961. In 1982 my mother came from Pakistan as a visitor. She was a school teacher. I am her only son. In our culture, sons are more responsible for the parent. When she wanted to retire, I asked her to come and stay with me and the Home Office agreed.

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 has burned clothes by putting them on a heater. She can't be left alone at all. Sometimes at night she removes her incontinence pads – she is doubly incontinent – and we have to change the bed clothes and her night clothes. Sometimes mum walks around in the night and we have to try to keep an eye on her.

In the last five years my mother has started to get dementia. My wife helps to take care of her. Social services said they would put my mother 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 my mum needs me. That is how it is to my mind.

One problem is that people assess dementia from the outside. I wish people could live with someone and then assess them. We need people who really have experience of and understand dementia patients. Also, I think there should be more recognition for carers. That should include financial support.





LESLIE





Leslie, 85, cares for his wife, Eve.

Eve has been diagnosed with dementia. My caring changes from day to day and week to week. 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. They have games and entertainment. I can get down to my jobs while Eve is away. I feel free.

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. I prepare meals and do the housework. I can't make the meals for Eve that my mother made for me, so I feel inadequate. Ready meals don't agree with me.

I pay someone to sit in with Eve while I go out. She is a lovely person and has been accepted by Eve as a friend. I go to a carers' meeting on Friday. It's like opening another door. I can get back to normal. The tension goes away and my head clears. We talk among ourselves and there is a pleasant atmosphere. We all have a tale to tell. I find out how other carers overcome their problems. It's an escape valve. You are with your own kind – 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.

CHRISTINE

Christine cares for her mother, Margaret.

My dad had died and my mother was up in North Wales with mobility problems and getting more and more isolated and depressed. So I asked her if she wanted to come and live with me and she snatched my hand off. She was 78. I thought, 'It's only for a few years. I can put up with that'. She's 92 now! So I came into it by accident – I didn't think I was a carer until I was labelled and told that I was.

To start with, she just lived with me and I was still working. But then in 2001 she had an infection in her knee replacement and had it replaced again, and then she got an infection in that. In the end, she had to have her leg amputated. So, suddenly, she was in a wheelchair, which changed life dramatically.

I had tried to carry on working in a very demanding job, until 2004 when I just keeled over one day. It took a year to get my health back. I was really forced into early retirement and full-time caring.

After she had her leg amputated we were given a care package. But then it got harder for her to cope as well. It was difficult for a while because there was no increased support package. So I just had to cope.

After I stopped work I didn't have the income, so I couldn't buy in help to run the house to give my time to her. Our finances nosedived, so I used up all my savings. We went from me having a good salary to living on benefits. It certainly wounded my pride to go onto benefits. My self esteem just plummeted. I'd never claimed anything in my life. Going to the Jobcentre was totally humiliating. In the end that just played on my health as well.

Then I understood what a carer is. Yes, I was quite happy to look after her, but I needed a break too. I didn't have a life of my own. If I could have got a break, I would just have gone for a swim, something like that. Be me, do what I want. I just needed to get out of the house or even go out with friends for coffee. So when that got to crisis point, they gave me four hours a week help, but it was better than nothing. Carers are entitled to a life of their own.





SHEILA





Sheila is 75. Her husband Tom is 77 and has had Parkinson's disease for five years, but helps with their disabled son, Craig, around the house. Sheila also cares for her mother and sister.

My son, Craig, has Down's syndrome. I am also a carer for my mum who is 98. She lives in a home. I take her food, wash her clothes, wash her hair and generally look after her. She sometimes spends time in hospital and I go to visit. I also have a sister who lives in a dementia centre. My care for her is mainly social. 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. I put him in the bath then he baths himself and I get him out again. I wash his hair. He can't be left alone in the house and we don't want to leave him alone. 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. I take care of getting his food and do things like fastening his shoes.

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. My health is generally good, but I get tired quicker. I get aches and pains and I suffer from arthritis.

Tom being diagnosed with Parkinson's disease was the trigger for thinking about Craig's long-term future and starting to look for other care for him.

What do I need? 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.

IRIS

Iris, 73, looks after her husband, who is 74.

Caring for my husband commenced in 1990 when he had a severe heart attack, followed by multiple strokes. Over the years he has lost speech, hearing, swallowing and 20 per cent of his vision. He also has reduced mobility and weakness. He has very challenging communication problems. I am his voice.

He is doubly incontinent, so needs 24/7 toilet care. He has recently been catheterised. I administer all feeds, water and medication through a gastrostomy tube. I care for the PEG⁷ site, all equipment and order supplies.

I accompany him at all times, carry out oral care and care of finger- and toenails, cut his hair, and help with dressing. I administer all his affairs. I try to stimulate a very active mind – his high intelligence is still intact.

I would like more crisis cover. At the moment, it is only available if both loved one and carer are ill at the same time. I would also like financial recognition of care that is given 24/7. Carers pay for the privilege of caring.

Those caring for people with strokes in the community don't get the same support as for cancer. Yet the effect on their family and friends is very serious. Professional support for strokes should be on a similar level to cancer support.

⁷ Percutaneous endoscopic gastrostomy: a means of feeding using a tube that passes through the abdominal wall directly into the stomach, so that nutrition can be provided without swallowing.







The new force combining
Age Concern and Help the Aged

Age UK

Astral House, 1268 London Road, London SW16 4ER
York House, 207–221 Pentonville Road, London N1 9UZ

020 8765 7200
www.ageuk.org.uk

Age UK is working locally and in partnership with Age Concerns.
Report printed October 2010.

Photography by Sam Mellish.