

The choice is mine

Why Attendance Allowance is so important to older people



Introduction

As we age, many of us will develop long-term illnesses and disabilities. And very often this means a higher price tag for day to day things that can support us to remain healthy and independent.

Attendance Allowance is a weekly payment that helps older disabled people meet some of the extra costs they face. But the Government has proposed passing responsibility for Attendance Allowance to councils in England, for those needing help in the future. This would create a 'postcode lottery' instead of a single national

scheme. And because the population is ageing, the need for support will rise, but councils may not be able to increase funding to keep pace with this growing demand. This means many older people who become disabled in future could miss out altogether.

Our research

Age UK surveyed 553 recipients of Attendance Allowance. We asked how it helps them now, and their response to the idea of future claimants like them approaching local councils for support. Their comments highlight the positive difference it makes to their lives today and the concerns they have if the proposed changes to Attendance Allowance go ahead.



Our open letter to Government

Dear Sajid Javid MP, Secretary of State for Communities and Local Government, Philip Hammond MP, Chancellor of the Exchequer, Damian Green MP, Secretary of State for Work and Pensions and Jeremy Hunt MP, Secretary of State for Health.

We are writing to voice our deep concern about the proposal to transfer responsibility for Attendance Allowance to councils.

We are extremely worried that this would create a patchwork of different approaches in place of a single national scheme that means older disabled people can decide the help they need. We are equally concerned that locally generated funds would be outstripped by the growing numbers of older people who will need Attendance Allowance in future, depriving them of help, undermining their independence and increasing burdens on other local services.

This proposal has huge implications for tomorrow's older disabled people and their families and we fear could effectively mean the end of a vital source of support.

We call on you not to include Attendance Allowance in the responsibilities transferred to councils.

How do people use their Attendance Allowance?

Older people told us they spend their Attendance Allowance in many different ways, reflecting their diverse needs. The main uses fell into three categories: practical help at home; transport to medical and other appointments; heating, eating and other daily costs.

Practical help at home

Three in five respondents said Attendance Allowance enables them to arrange practical help such as cleaning, gardening and laundry, without which they would struggle to cope with running a home. Only around one in ten mentioned using Attendance Allowance to pay for some help from a carer or support from a day centre or other local resource.



59%

said Attendance Allowance **helped pay for practical help** at home.

'I am not able to do housework and I pay my cleaner with this. I am incontinent and go through a lot of clothing and bedding.'
(Female 70-79)

'(Without Attendance Allowance) I wouldn't be able to pay for a cleaner or gardener as we're both only on basic pensions.'
(Couple 80-89)

'(Without Attendance Allowance) I couldn't afford the Day Centre and pay for the gardener and cleaner.'
(Female 70-79)

'I employ a carer every day to help with the shower and dressing and housework.'
(Female 80-89)

Transport to essential appointments

Our survey showed how important Attendance Allowance is in helping older disabled people to get out and about, stay connected to their community, do their shopping and attend medical appointments.

It found a much higher proportion of respondents (56 per cent) used the benefit to get to essential appointments compared with findings from a very similar survey we conducted in 2007/8, when just 13 per cent used it for any kind of travel.



56%

said they used Attendance Allowance **to get to essential appointments.**

'I have difficulty walking and can't carry shopping; the Attendance Allowance pays for taxis to the supermarket.'
(Female 80-89)

'I would find it difficult to get to GP and hospital appointments by public transport - I can get taxis now.'
(Male 70-79)

'I would find it difficult to budget for visits to my wife who is resident in a care home some 20 miles away. I am 91 and find it difficult to use public transport.'
(Male 90-100)

'I was unable to afford transport to doctors and wellbeing appointments. It's helped me to get out and ease the loneliness.'
(Female 70-79)

Heating, eating and other everyday costs

Just over one in three respondents said they spent their Attendance Allowance on extra heating and food. Many disabled people need to keep their homes particularly warm or need more expensive special diets because of their health conditions – these are big concerns, for example, for those living with cancer and diabetes.

The survey also showed how Attendance Allowance enables older disabled people to acknowledge the support they receive from friends, relatives and neighbours through offering ‘petrol money’ and the like, encouraging them to ask for and receive help they might otherwise choose to go without.



said Attendance Allowance helped pay for heating, food and everyday costs.

‘I would feel sad as the payment helps me to purchase better food which helps with my health.’
(Male 70–79)

‘Without AA extra heating would be beyond my means. I am in constant pain and greatly reduced mobility.’ *(Male 80–89)*

‘(Without AA) I would be extremely worried and unhappy. I would not be able to afford good food, heating and warm clothing and bedding’ *(Male 80–89)*

‘I pay my neighbour for help washing/showering and dressing etc. Can’t manage without and would need to go into care.’
(Male 70–79)

‘I also pay some fuel money to my daughter as she helps me with personal care and takes my heavy washing to do in her home.’
(Female, 70-79)

The difference Attendance Allowance makes

We asked respondents to imagine how life would be if they no longer received Attendance Allowance (while emphasising the Government’s proposals only apply to future recipients). A bleak picture emerged and the comments given illustrate how much older disabled people value the choice, control and dignity Attendance Allowance gives them.

‘When I get my Attendance Allowance I can decide which is the most important and essential thing I want to do with it and some weeks it varies. If I had it from the council they would decide how it is spent.’ *(Male 80–89)*

‘I would be less happy, would feel less cared for, less well physically because I’d be struggling to do chores and gardening myself. Less content. AA has given me more choices and independence.’
(Female 70–79)

‘I would lose my independence, have to cut back on essential items and not have the peace of mind that the bills would be paid. It would mean the difference between living and existing.’
(Female 70–79)

‘I’ve struggled all my life to make ends meet. I’m 94 now, still live on my own without family to help, and this is the first time that I don’t have to worry about money.’
(Female 90–100)



Carmel's story

Carmel, 84, lives alone in a maisonette in North London. She has a number of health issues including diabetes and poor mobility. Last year she was diagnosed with Alzheimer's. Her family are her main carers, especially her daughter Pat, and one of her sons who lives next door. Pat tells of how they applied for Attendance Allowance soon after her mum was diagnosed with Alzheimer's:

'A chap from the Department of Work and Pensions helped me fill in the forms – he was really helpful. Mum got the Attendance Allowance for day and night attendance. It was really straightforward in the end.'

Pat said they were delighted when they heard Carmel was to get Attendance Allowance. 'It meant that my brother got the Carers' Allowance, which has enabled him to give up some work (he's a self-employed painter/decorator) to help mum more. The money has helped pay for

her increasing care needs. She was supposed to get an assessment from Social Services after she got out of hospital six months ago but it didn't happen... If she hadn't had her family to help her, where would she be? The council are just overstretched.'

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Audrey and Ricky's story

Audrey and Ricky are 71, married for 46 years and have one daughter. They met in Scotland in the 1960's when Ricky was a member of a local band. Both were recently awarded Attendance Allowance.

Audrey is recovering from breast cancer and suffers from osteoarthritis and osteoporosis. Arthritis in her feet has led to the amputation of two toes and mobility is a problem. Ricky has had numerous operations on his face and mouth for cancer and has on-going heart and breathing problems which means he gets tired and breathless very easily. They are still able to manage without help in the home by 'pacing themselves'. Audrey says they are much less worried now they are getting Attendance Allowance, particularly about the cost of heating their home in winter:



'It's surprising how it makes you feel, getting that extra money. You feel you can cope better.'

'We don't need to watch the pennies so much. It gets very cold up here in Darlington and since my cancer I really feel the cold terribly. I had to think twice about burning extra fuel last winter.

It's surprising how it makes you feel, getting that extra money. You feel you can cope better. It may sound silly but you think I can do this, I can do that, I can turn the heating on. I have this extra bit of money behind me and I feel more secure.

If the local council was responsible for Attendance Allowance, well no. They just don't listen to us do they? They make a show of listening, but they don't really. Their attitude seems well, negative somehow.'

Mabel's story



Mabel is 94 and lives in Ashford, Kent. She is from a military family and served in the Armed Forces during the Second World War as a Staff Sergeant. Last year she was very proud to be able to attend the VE Day anniversary parade in Whitehall.

Her daughter Sue is her main carer, although Mabel still lives alone and is fiercely independent. Impaired eyesight and general frailty mean that she can no longer manage her garden or do much housework.

Keeping her garden neat and tidy was a big worry for Mabel, and Attendance Allowance has now allowed her to

pay for a gardener. She can also afford to pay for service washes at the launderette which means her daughter no longer has to do all her washing and ironing. As Mabel is increasingly frail and susceptible to falls, Sue is pleased that the extra money allows her mum to afford to have a personal alarm, which gives them both peace of mind.

Approaching the council for support instead

Only one in five respondents had been in contact with their council for care support and just one in seven (14 per cent) said they received it. This is very similar to national estimates which show that the majority of today's Attendance Allowance recipients manage without care or support services from their council, even though they are coping with quite serious disabilities and health conditions.

When we asked 'Would you be happy to approach your council for support such as Attendance Allowance?' around four out of five were unsure or said 'no'. Comments showed people liked the system the way it is or expressed concerns about possible changes.

The concerns they raised related to how councils would manage the extra workload and some questioned whether their council would be resourced to respond to the problems experienced by older disabled people like them.

'I would prefer it if it could stay with DWP – my council has made so many cut backs with ever more threatened. I do not feel they would be able to afford to make AA payments, which I need to keep my independence.' (Female 90–100)

'They were no help whatsoever! Hasn't got any idea of my problems and health issues.' (Male 60–69)

'I am not sure how helpful they would be, as I trust the present system much more than the council.' (Male 70–79)

'I have the greatest respect for the council but they do struggle each year against funding cuts. These obviously have to be passed on – but please, not to the elderly and infirm!' (Female 80–89)

Attendance Allowance works

Seven out of ten of our survey respondents said Attendance Allowance makes a positive and valuable difference to their ability to stay independent. A key theme that emerged was that receiving Attendance Allowance in its cash benefit form offered them peace of mind, dignity, choice and control, which were extremely important to them.



'(It would be) nicer to keep it the way it is because I have more control over this.' (Male 80–89)

'Without Attendance Allowance I would feel less happy, less cared for, less well physically because I'd be struggling to do chores and gardening myself. Attendance Allowance has given me more choices and independence.' (Female 70–79)

'(Without Attendance Allowance) I would lose my independence, have to cut back on essential items and not have the peace of mind that the bills would be paid. It would mean the difference between living and existing.' (Female 70–79)

Conclusion

This latest research confirms findings from previous Age UK surveys, and shows that Attendance Allowance makes a big practical difference to the older disabled people who receive it.

The feedback we have been given shows just how important it is to them that Attendance Allowance is maintained as a cash payment at a single national level.

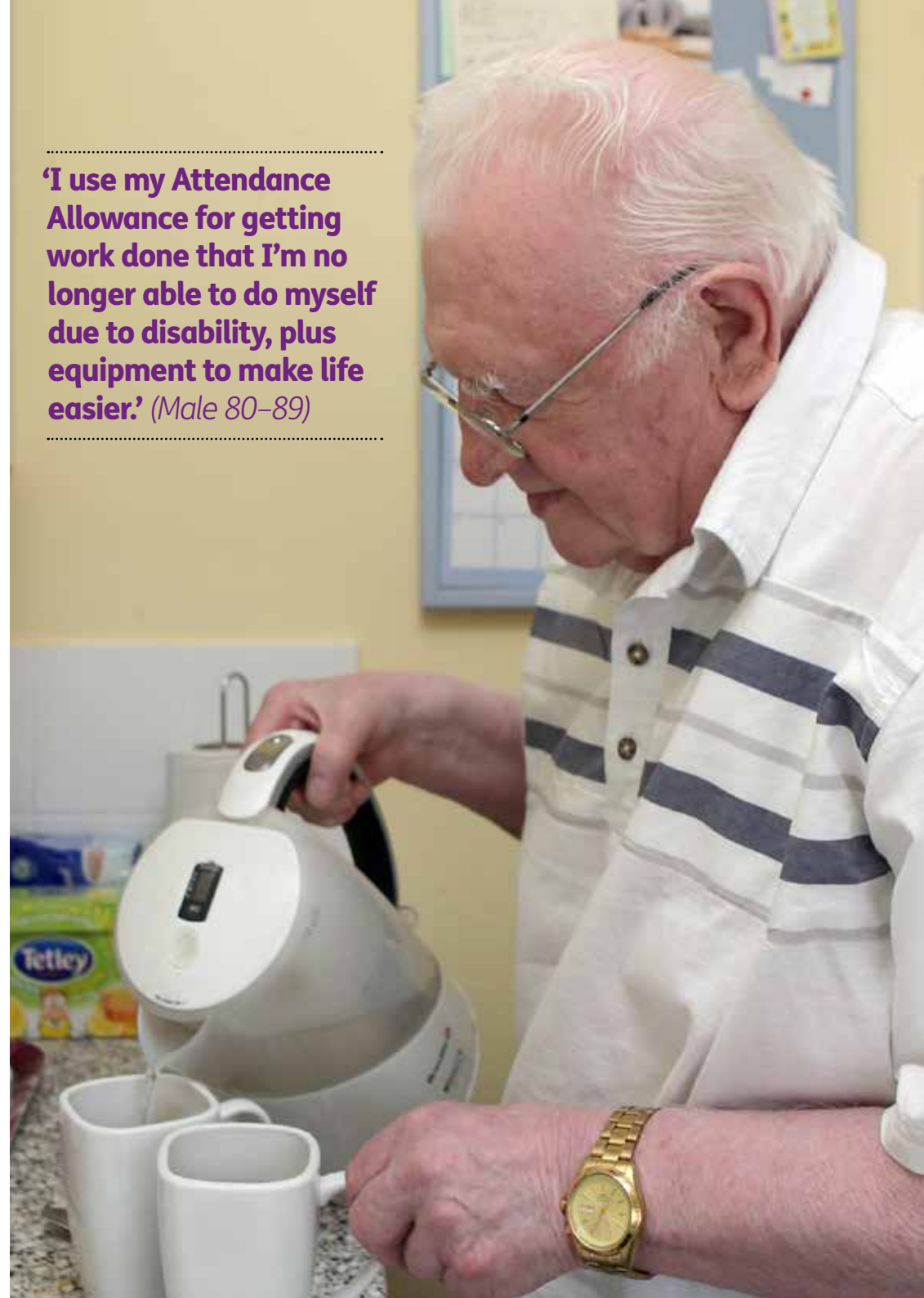
This is because in this form it gives older disabled people two things which are clearly very important to them: clarity about what they will receive and the flexibility to spend it as they see fit. And Attendance Allowance not only helps older disabled people to cope at home for longer, it also supports the making of informal care arrangements, the value of which vastly outweighs the contribution of the State. Age UK believes we undermine the kindness and commitment of families, neighbours and friends at our peril.

As well as creating a patchwork of support for new claimants right away, we are concerned that the ability to raise funds from business rates will be unable to keep pace with the growing numbers of older people who would need Attendance Allowance. It is therefore not surprising that councils have said that they don't want the transfer to take place.

Any move to transfer Attendance Allowance would have huge implications for older disabled people in the future and could effectively represent the end of this vital means of support.

In Age UK's view, transferring responsibility for Attendance Allowance to councils would be the wrong policy choice for older disabled people and their families so we urge the Government to think again.

'I use my Attendance Allowance for getting work done that I'm no longer able to do myself due to disability, plus equipment to make life easier.' (Male 80-89)



Attendance Allowance makes a big practical difference to older disabled people who receive it. Our survey shows how important it is to recipients and their families. Age UK believes that transferring responsibility for Attendance allowance to councils would be the wrong policy choice for older disabled people and we urge the Government to think again.

You can get involved by:

Visiting www.ageuk.org.uk/attendanceallowancecampaign

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Writing to us

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