



ROOM TO MANOEUVRE

Why aids and adaptations
matter to people with arthritis

CONTENTS

Introduction	3
What are aids and adaptations?	5
Our findings	9
What you can do	11
Why aids and adaptations matter	13
Promoting the possibilities: information and advice	17
Paying the price: funding aids and adaptations	21
Safe as houses: the Disabled Facilities Grant	25
Time to ramp up support	29

1 / INTRODUCTION

Arthritis and other musculoskeletal conditions are the number one cause of disability in the country. Over 17 million people in the UK have musculoskeletal conditions. By 2050 rheumatoid arthritis and osteoarthritis will affect one in five people in the UK. This means that in every local area there are large numbers of people living with long-term pain, who need care and support from health and social care services.

Arthritis impacts every aspect of someone's life. From getting dressed and going to work, to cooking meals and spending time with family and friends. People with arthritis cannot take these moments for granted. Many people spend years

living with severe pain and fatigue, which has a knock-on impact on their mental health. With the number of people affected rising, action is needed so that people with arthritis feel supported to live full and active lives.

We believe that aids and adaptations can support people to lead more independent lives and reduce the risk that they will need more intensive, and expensive, services. However, it is vital that both local and national government does everything it can to ensure the current rules and regulations are followed.

We have discovered that many people with arthritis don't even know what help exists.



If someone with arthritis is assessed as eligible, local councils have a legal duty to provide aids and minor adaptations to that person without charge. Councils also have a legal duty to supply information and advice on how to access other types of support in the form of grants for major adaptations.

Despite national and local policies to ensure good

provision of aids and adaptations for the home, we have discovered that many people with arthritis don't even know what help exists, let alone that some aids and adaptations should be provided without cost to them. Consequently, many people with arthritis are living without equipment that could improve their quality of life, or they are spending large sums of their own money on them.

2/ WHAT ARE AIDS AND ADAPTATIONS?

▼ **Aids** help people to manage everyday tasks such as bathing, dressing, and cooking.

▼ **Adaptations** are more substantial additions or alterations that primarily help someone to move

freely around their home. An adaptation can be minor and cost less than £1000, or major and cost more than £1000.

A high proportion of people with arthritis would be eligible for aids.



EXAMPLES OF AIDS AND ADAPTATIONS USED BY PEOPLE WITH ARTHRITIS

AIDS	ADAPTATIONS
<p> ▲ Aids for dressing: shoehorns, boot grips, knee supports. </p> <p> ▲ Kitchen aids: soft or wide handled cutlery, adapted kettles, two-handled saucepans, dishwashers, microwaves, electric can openers, food processors. </p> <p> ▲ Aids for resting and standing: perching stools, banisters, rails or handles, high stools. </p> <p> ▲ Aids for assisting with housework: ‘grabbing’ tools, a trolley for moving items, upright hoovers, lever handles on doors, touch lamps. </p> <p> ▲ Aids to help with washing: tap turners/lever taps, bath seats, raised toilet seats, shower seats, seat adjusters. </p> <p> ▲ Aids for staying mobile around the home: portable ramps, slide sheets, soft knee pads, wheelchairs. </p> <p> ▲ Aids for sleeping: adjustable beds, beds that raise you up, hot water bottles, gloves to reduce pain when sleeping, specialist mattresses. </p>	<p> ▲ Adaptations to help with mobility around the home: automatic doors for wheelchairs, doorways widened for wheelchair access, fixed ramps, graded/sloping front drive, stair lifts, wheelchair lifts. </p> <p> ▲ Adaptations to help with bathing: baths with built-in handles, fixed hoists, major permanent bathroom changes e.g. walk-in bath/wet room. </p>

Who should qualify?

To be offered aids and minor adaptations, people need to meet the eligibility criteria. They must have a physical or mental illness or disability, and be unable to do basic tasks or activities, such as cooking, eating, washing, going to the toilet, dressing, cleaning, working, and/or developing and maintaining family and social relationships.

If being unable to do two or more of these tasks or activities has a significant impact on that adult's well-being, they should qualify for aids and adaptations.

If an adult has a condition that fluctuates, such as rheumatoid arthritis, the local authority must take into account the person's situation over a period of time to accurately establish how much support they need.

In our study, over half (55%) of respondents with musculoskeletal conditions were unable to achieve two or more of the activities listed. This suggests that a high proportion of people with arthritis would be eligible for aids and minor adaptations free of charge from their local authority.

Is this a UK wide issue?

This report relates to England only, because health and social care policy is devolved to national governments in Scotland, Wales and Northern Ireland. We have teams in each nation working to ensure that people with arthritis have access to the support that they need.





What does the legislation say?

The rules governing the provision of aids and adaptations come from two different pieces of legislation:

- the Care Act 2014
- the Housing Grants, Construction and Regeneration Act 1996.

Under the Care Act, local authorities have duties to promote well-being, and to provide, or arrange for, services intended to prevent, reduce or delay care and support needs for adults

and carers. Within the Acts, there are four specific responsibilities, two are universal for people with arthritis, and two concern the provision of aids and adaptations:

- providing information and advice
- assessing, and meeting, people's care needs
- providing community equipment
- meeting the housing needs of people with disabilities, including the provision of Disabled Facilities Grants (DFG).

3/ OUR FINDINGS

To learn more about the issues surrounding aids and adaptations we conducted an in-depth survey asking 1,000 people across England with musculoskeletal conditions to share their views,¹ as well as interviewing individuals and professionals working for local authorities.

■ Many people with arthritis are living without the equipment that could improve their quality of life or are spending large sums of their own money.

■ 95% of respondents using aids and adaptations felt that this support had a positive impact on their quality of life.



■ 79% of survey respondents said aids and adaptations improved their ability to be independent.

■ 13% of respondents said aids and adaptations helped them achieve independence.

¹Arthritis Research UK (2018). *Findings taken from ICM Unlimited (2016): Aids and adaptations research, and Revealing Realities (2016): Arthritis Research UK Aids and Adaptations.*

Paying the price

□ Over 50% of people eligible for aids and adaptations who responded to our survey are purchasing them themselves, while less than 16% are getting them from their local authority.

□ The average cost of an aid in our study was around £200.

Promoting the possibilities

□ One third of people sought information, but only 1 in 10 said that their local authority was their main source of advice.

□ Almost 20% were not using aids or adaptations at all.

□ Of these, over 85% were unaware their local authority has a duty to provide this type of equipment and 1 in 10 said cost was a barrier.

Safe as houses

□ 1.8 million people with disabilities are living with unmet housing needs.

□ People can be left waiting years for a major adaptation and many councils have a huge backlog of applications.

4/ WHAT YOU CAN DO

For people with arthritis to access the aids and adaptations they need to improve their quality of life, improvements must be made to the current system.

What can MPs and peers do?

- Tell the Secretary of State for Health and Social Care about challenges that your constituents face accessing aids and adaptations.

- Ask the Secretary of State for Health and Social Care to commission an expert body to develop a centralised resource focused on aids and adaptations including best practice guidance on the provision of information and advice, how aids and adaptations can be used as part of an agenda to reduce or delay care needs, and evidence of return on investment.

- Ask the Secretary of State for Health and Social Care to ensure that the external review of the Disabled Facilities Grant (DFG) considers the means-test, the speed of the application, and how variation in provision can be addressed, to ensure that people with arthritis can access these grants on an equitable and timely basis.

- Ask the National Audit Office to consider conducting an audit of the provision of ‘community equipment’, including local authority and clinical commissioning group spending.



What can local authorities do?

- Meet their legal duties as set out in the Care Act 2014 by ensuring that local residents with arthritis have their needs assessed, and that those who are eligible are provided aids and minor adaptations free of charge.

- Work with local partners and stakeholders to evaluate the local authority's information and advice on housing, and aids and adaptations, to ensure it meets the needs of people with arthritis, and is easily accessible.

- Ensure that people with arthritis have fair access to aids and adaptations, by not limiting provision by introducing caps below the £1000 threshold set out in the Care Act.

What can people affected by arthritis do?

If you want to help us fix this system, but you aren't sure how to influence decisions at a local or national level, you can join our campaign network to call for change at arthritisresearchuk.org/campaigns

5 / WHY AIDS AND ADAPTATIONS MATTER

Arthritis Research UK wants people with musculoskeletal conditions to feel in control, and positive about the future.

Home aids and adaptations are one aspect of services that can reduce or delay needs for care among people with arthritis. In a 2015 survey, 96% of the occupational therapists who responded said that home adaptations reduce the need for formal social care.² Alongside this, our study found that 95% of respondents using aids and adaptations felt that this support had a positive impact on their quality of life. Maintaining independence is a crucial aspect of this, and 79% of survey respondents said aids and adaptations improved their ability to

be independent. For some, this support is even more impactful, with 13% of respondents saying aids and adaptations helped them achieve independence.

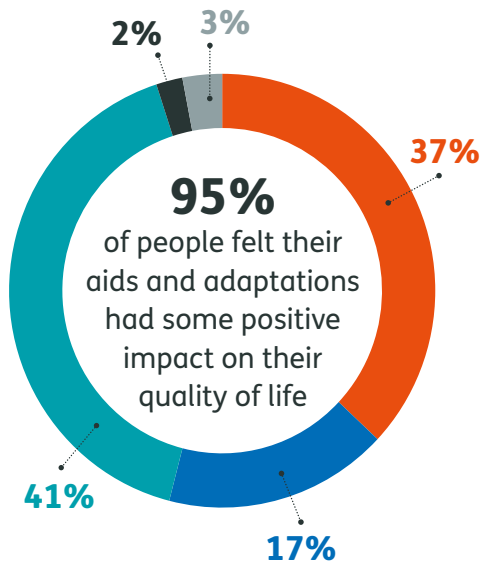
By supporting independent living, and preventing accidents and injury, we believe aids and adaptations may have a long term positive impact on health and social care costs.

In addition we know that some people living with chronic pain, including arthritis and back pain, are on low incomes or live in deprived areas.^{3,4} We believe providing aids and minor adaptations free of charge could benefit people in this situation by reducing additional costs they might face.

Aids and adaptations improved my quality of life

- A fair amount
- A great deal
- Just a little
- Don't know
- Not at all

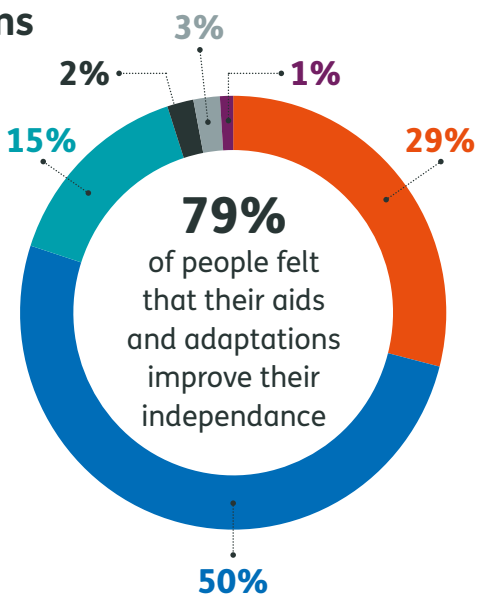
People with musculoskeletal conditions were asked 'Overall, what impact do the aids and adaptations you have in your home have on your quality of life?'
Total number of respondents = 637



Aids and adaptations help me maintain my independence

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don't know

People with musculoskeletal conditions were asked 'how much do you agree or disagree that the aids and adaptations you have in your home help you maintain your independence?'
Total number of respondents = 637





JACK'S STORY: “I’ve had a very active, outdoor life. I’ve been all over the world. I used to work with horses and dogs; I bred dogs, and even won a prize at Crufts and judged competitions. Now I’m 68 and have multiple health conditions. It’s just impossible to do the things I used to do, but I live alone and am very independent which I don’t want to give up. I was

diagnosed with osteoarthritis in my hips and spine three years ago, and it has really affected my mobility. The arthritis in my spine caused progressive paralysis and I’ve had operations to stop it getting worse. I also had a fall, which really knocked my confidence. The doctor suggested I get myself some crutches, which have made me feel much more stable and

steady. They're definitely my most important aid, but I use many others. I love cooking, but I find it difficult because I don't have any feeling in my fingers, so they are vulnerable to nicks and burns.

“The doctor suggested I get myself some crutches, which have made me feel much more stable and steady.”

Even slicing a carrot can be quite dangerous and I often end up cutting my fingers. I've managed to find kitchen implements that help, including special knives, a chopping board that grips vegetables, a one-handed tray which I can carry while using my crutch, and

a long grabber to reach the top shelf of my cupboards. Overall, using these aids has helped my independence and meant I can carry on as normally as possible. Going out and socialising would be impossible without them; I would be housebound.”

Legislation is already in place to ensure that people in England have access to the aids and adaptations they need, with duties in the Care Act on local authorities to make sure this is happening. However, our research findings, and the testimony we've heard from people with arthritis, has demonstrated that not everyone is getting what they need.

²College of Occupational Therapists carried out a survey with OTs with a specialism in housing in 2015, which received 104 responses.

³Health and Social Care Information Centre (2012). *Health Survey for England 2011*, volume 1. Chapter 9, Chronic Pain

⁴GP Patient Survey (2014). Analysis conducted by Arthritis Research UK

6 / PROMOTING THE POSSIBILITIES

■ What's the problem?

Good information and advice empowers people with arthritis to be in control of their condition. Aids and adaptations are one aspect of services that can reduce or delay needs for care among people with arthritis, and help maintain independence. But many people living with arthritis don't know that this type of help exists, or how they could benefit. One fifth of people with musculoskeletal conditions, who took part in our research and have eligible needs, are not using aids and adaptations and almost one in ten of those said cost was a barrier. Worryingly, many of those who successfully sourced information from their local authority had 'insider knowledge', for example they are professional care workers.

■ What should be

happening? Local authorities have a legal duty under the Care Act 2014 to provide, or arrange for, services to prevent people developing needs, and delay the impact of an existing disability. The regulations accompanying the Care Act also state that there is an expectation for local authorities to promote accessible information and advice on aids and adaptations to ensure local residents know what help is available to them, and how they can receive it.

Aids and adaptations are one aspect of services that can reduce or delay needs for care among people with arthritis.



▼ JENNYLYN'S STORY:

“I was 31 and a teacher when I was diagnosed with rheumatoid arthritis. My diagnosis happened very quickly and out of the blue. It was a big shock and a lot to take in. I had to start using crutches because both my knees needed replacing. I got in touch with the occupational therapy team at the council, and a lady came round and

offered me a raised toilet seat. I was sort of happy enough with that. Even though I was finding it very difficult, I didn't really know what I needed or what I should be asking for. Luckily for me my sister works for a council and when she heard about the toilet seat she said: “Jenny, that's rubbish, you need to get hold of the right person”. I got in touch again and managed to get

a full home assessment this time. As soon as the second occupational therapist saw me struggling to walk, I knew she was going to help me. Over the years I've been assessed by various professionals and have been provided with grab rails in my bathroom, a kettle tipper, a jar opener, a ring pull gadget to open cans, and raised plug sockets around my house. I've also bought lots of aids myself. I think it's all at the discretion of the person who comes to your home, which shouldn't be the case. I feel if I hadn't asked and pushed for these things, I wouldn't have got them."

■ **Key stats:** Almost 20% of people with musculoskeletal conditions who have eligible needs, and answered our survey, don't use aids and adaptations. Within this group, over 85% were not aware of the local authority duty to provide community equipment. In our study, one third of people with

musculoskeletal conditions sought information and advice, but only one in ten told us that their local authority was their main source of information and advice.

■ **NATASHA'S STORY:** *"Just before I got diagnosed with rheumatoid arthritis, I was in my mid-twenties looking after my young daughter, and I was feeling good about the future. I was going to the gym regularly, and was probably the fittest I'd ever been. But then I started feeling pain in my feet and knees, which moved to my shoulder and became excruciating. I was diagnosed with rheumatoid arthritis, and I fell into a deep depression. The condition has progressed quite quickly. Some*

"These aids could be life changing for me, but no one has ever mentioned them."

days are worse than others, but every day I'm in some sort of pain. The condition means I find basic tasks quite a challenge. Food shopping is frustrating, as even carrying a few pints of milk is impossible. When I wash myself, or bathe my young daughter, it really hurts my wrist and back. When cooking, despite buying the lightest pans I could find, I can't move them from the stove when they're full. In bed I turn a lot during the night as my shoulders and back hurt when I lean on them. I invested in a memory foam mattress recently, but I wish I could have an electric adjustable bed. I often get frustrated with myself and feel quite low. I wish I didn't have to ask for help. I couldn't believe it when Arthritis Research UK told me that there are gadgets which could help me around the house. These could be life changing for me, but no one has ever mentioned them!"

▼ **What can MPs**

and peers do? Tell the Secretary of State for Health and Social Care about challenges that your constituents face accessing aids and adaptations. Ask him to commission an expert body to develop a resource focused on aids and adaptations including best practice guidance on providing information and advice, how aids and adaptations can be used as part of an agenda to reduce or delay care needs, and evidence of return on investment.

▼ **What can local**

authorities do? Work with local partners and stakeholders to evaluate their information and advice on housing, and aids and adaptations, to ensure it meets the needs of people with arthritis.

7 / PAYING THE PRICE

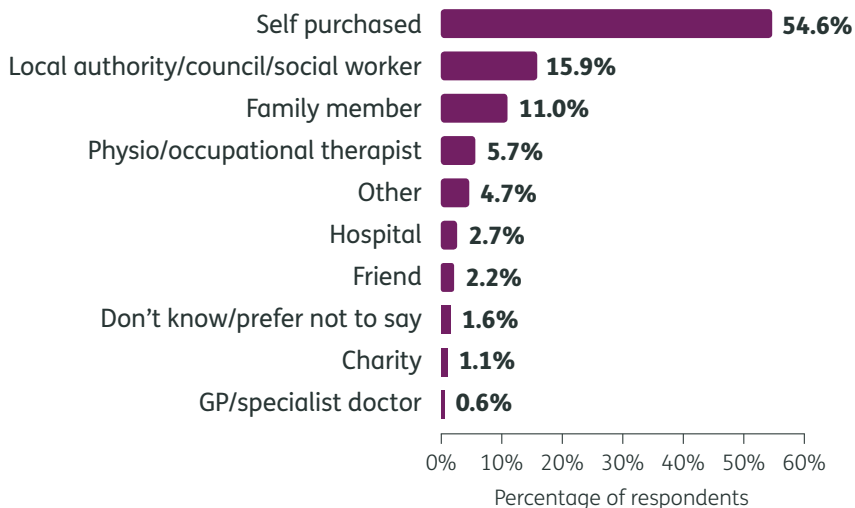
■ **What is the problem?** If people overcome the first barrier of finding out they can approach their local authority for information and advice, they are often not told that they can access aids and minor adaptations for free.

People with arthritis have told us they've been advised to buy items online. Some aids and adaptations are a relatively low price, while others, such as electric adjustable beds or chairs, can be more expensive. When people with arthritis need multiple items, the costs can quickly mount up, with the average cost of an aid in our study at around £200. In our research, cost was one of the most common reasons why people said they didn't have an aid or adaptation.

We are also concerned by testimony from some health professionals stating that their local authorities have put limits on what they will provide, either by saying they will not pay for anything under a certain amount (for example £20) or capping the total at a lower amount than the Care Act requires, such as £500 instead of £1000.

Our study found that 54% of respondents who bought aids and adaptations individually, said they had difficulty sourcing any from their local authority. Small setbacks often deter people, some feel that whoever they speak to at their local authority 'knows best', and many do not persist with their enquiries, even when their circumstances change.

Where are people getting their aids and adaptations?



■ **Key stats:** Over half the people with a musculoskeletal condition who answered our survey have eligible needs.⁶ Of this group:

□ Over 70% are using aids and adaptations.

□ Just over 15% are aware of the duty for local authorities to provide aids and adaptations.

■ **What should be happening?** Anyone can ask for a needs assessment, and the local authority has

a legal duty to conduct one to determine whether a person is eligible for care and support, including community equipment such as aids or minor adaptations (of less than £1000).

When someone is found to have eligible needs, the local authority must legally meet these needs, if the person wishes it to do so. People living with arthritis who meet the eligibility criteria should be offered aids and minor adaptations free of charge.



▼ CHRISTINE'S STORY: *I've had osteoarthritis since the age of 19, and took the attitude that it wouldn't beat me. Over time it's affected different parts of my body, including my hands, hips, knees and neck. Just making a cup of tea and other tasks around the kitchen can be complicated. Over the years, I've bought various aids and gadgets to manage my arthritis. I didn't realise how much an electric tin opener or gripping plastics*

could revolutionise my life. I recently thought about getting an adapted bread knife so I can cut bread more easily, but I have held off until I have a bit of spare money as I also need to install some expensive quarter turn taps in my kitchen. To continue gardening, I've bought knee pads and sprung secateurs. When we were able to afford it we adapted the bathroom with a walk-in shower so that I can wash without fear of falling. I also

have lever taps on the hand basin and replaced the toilet with one that has a button flush instead of a handle. The cost has really mounted up; the adaptations in the bathroom alone came to over £3000, but it was necessary so we just had to get on with it. I was shocked to discover, after talking to Arthritis Research UK, that I might be entitled to some of these items free of charge from my local authority. I know councils are under financial pressure, but these aids and adaptations are invaluable, helping people like me to manage my condition at home. Having access to them may mean I need to rely less on services provided by the council or the NHS. It is quite sad that I only found out about local authority support after spending so much of our own money.

What can MPs and peers do? Ask the National Audit Office to consider conducting an audit of the provision of ‘community equipment’,⁶ including local authority and clinical commissioning group spending.

What can local authorities do? Meet their legal duties as set out in the Care Act 2014 by ensuring that local residents with arthritis have their needs assessed, and that those who are eligible are provided aids and minor adaptations free of charge. Ensure they do not limit provision by introducing caps below the £1000 threshold set out in the Act.

⁵Provision of community equipment is set out in The Care and Support (Preventing Needs for Care and Support) Regulations 2014. www.legislation.gov.uk/uksi/2014/2673/pdfs/uksi_20142673_en.pdf

⁶Under Care Act Eligibility Guidance

8 / SAFE AS HOUSES

■ What is the problem?

Many people live in homes that do not meet their needs. This is no surprise when you consider that only 6% of existing housing meets the minimum requirements for accessibility that would allow people with disabilities to even visit.⁷ For people with care and support needs living in unsuitable housing, minor adaptations are unlikely to offer substantial enough improvements. They need major adaptations such as stairlifts, wet rooms, downstairs toilets, or having doorways widened to accommodate a wheelchair. Disabled Facilities Grants (DFGs) can provide crucial funding to pay for these changes. However, several problems emerged from our study of people with arthritis:

□ Many people with musculoskeletal conditions that could benefit from DFGs are unaware that this funding exists.

□ There can be a long wait for grants and applications to be approved. We have heard that in some councils the process is so long that people can be left waiting years for a critical major adaptation, and many councils have a huge backlog of applications.

□ Means-testing is intended to ensure resources are spent on those most in need. However, the means test doesn't take into account someone's outgoings. This disadvantages those with high monthly payments such as a mortgage or childcare

costs. In addition, the criteria have not changed much since being introduced in 1996, but the cost of living is far higher now.

Due to these barriers, some people told us they considered paying for adaptations themselves, but found the costs to be more than they could afford. In 2015 the Government committed to increase DFG funding up to 2020 as part of the Better Care Fund. This shows some recognition of the importance of major adaptations, but many people with arthritis still aren't getting the help they are entitled to.

▀ **Key stat:** 1.8 million people with disabilities are living with unmet housing needs.⁸

▀ **What should be happening?** People with musculoskeletal conditions

should be informed about the option to apply for a DFG for major home adaptations (of more than £1000). The DFG is underpinned by the legal duty for housing authorities to meet the needs of people with disabilities in the Housing Grants, Construction and Regeneration Act.

▀ **What can MPs and peers do?** Ask the Secretary of State for Health and Social Care to ensure that the external review of the DFG which has been commissioned considers the means-test, the speed of the application, and how variation in provision of DFGs can be addressed. It should ensure that people with arthritis are able to access these grants on an equitable and timely basis.

▼ CATHERINE'S STORY:

I've had rheumatoid arthritis since I was 12 years old. I use crutches and a wheelchair on a daily basis to stay mobile. I'm now having work done to adapt my house using a DFG. I was told by the person assessing my home that it was unsafe for me to live in; hearing that gave me a real sense of panic.

I'm relieved the work is underway, but the process of obtaining the grant was the most frustrating experience I've had in a long time. Information was very hard to come by, and even after the grant was approved there was little support from my local authority.

The onus is on the individual throughout the process, including finding quotes from

contractors. The upper limit of the grant is £30,000, but unfortunately I was told it would cost more than this to have all the adaptations I need, so I've had to prioritise.

“The onus is on the individual throughout the process, including finding quotes from contractors.”

It took 16 months from getting an assessment by an occupational therapist to the work starting. Even now that the builders have arrived, I haven't been told how long it will take to complete and I've been stuck inside while the work drags on. I've got a lot more grey hairs than a year ago.

^{7,8}The Papworth Trust and Habinteg (2017). The hidden housing market: A new perspective on the market case for accessible homes. www.papworthtrust.org.uk/sites/default/files/The%20hidden%20housing%20market.pdf.



9 / TIME TO RAMP UP SUPPORT

With the number of people with arthritis rising, action is needed now. At Arthritis Research UK we want everyone with arthritis to lead a full life. To achieve this, they need appropriate and relevant information and advice, which is promoted to them in a clear and accessible way. They should also be informed about their entitlements to aids and adaptations, and that these can be funded by their local authority.

We know there are challenges when it comes to ensuring everyone with arthritis has access to the help they need, not least because local authority adult social care budgets are under immense pressure. However, local authorities are legally required to assess

the eligibility of people with arthritis and other musculoskeletal conditions for aids and adaptations. If they are found to be eligible, the local authority also has a legal duty, under both the Care Act 2014 and the Housing Grants, Construction and Regeneration Act 1996, to provide aids and adaptations to that person without charge. In addition they have a legal duty to provide information and advice on how the system works, and to communicate how to access grants for major adaptations.

Though our research has shown that aids and adaptations can help people with arthritis to stay independent for longer, it has also revealed that large



numbers of people who could be eligible do not know what they are entitled to. As a result, many people fund their own aids and adaptations, at high personal cost.

Aids and adaptations can be a cost-effective way of supporting people with arthritis. By helping people to manage their condition effectively, these modifications may also relieve pressure on the health and social care systems. Local and national decision

makers should address the problems with the provision of aids and adaptations to ensure that people with arthritis are supported to live independently and lead full and active lives.

Get in touch

If you would like to talk to us about this report, or hear more about our policy work on aids and adaptations, get in touch with our team at action@arthritisresearchuk.org



For further information or to find out more about the work we do, visit our website or get in touch.

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