



Painful Journeys

Why getting to hospital appointments is a major issue for older people

Introduction



For most of us just having a hospital appointment is enough to worry about, but imagine having to make a long and complicated journey alone, in pain and and feeling anxious about not getting there in time. This is the reality for many of the older people we have heard from.

Often driving to their appointments is simply not an option. Many people we've spoken to don't have a car, cannot drive due to their condition or have no friends or family to take them. Even if they can go by car, many struggle to find hospital parking or the cost of parking is prohibitive.

If older people cannot actually get to the services they need, or have to endure long, painful and stressful journeys in order to access medical treatment, this will mean extra costs for the NHS due to missed appointments, possible relapses and treatment at a point of crisis rather than preventative care.



Our research

Age UK has found that 1.45 million people aged 65+ find it 'difficult or very difficult' to travel to hospital appointments.¹

We asked our supporters and a nationally representative sample of people aged 65+² to tell us about their experiences of travelling to hospital appointments.

There are three key problems that older people and their families say they face when trying to get to routine hospital appointments:

- **Long and uncomfortable public transport journeys to and from hospital**
- **Patient transport services are of variable quality**
- **Extra costs to older people and their families**

From our survey we found:

- Four out of ten (**41%**) people aged 65+ (and nearly half - **48%** - of those aged 76+) live with a health condition which requires them to attend hospital appointments.
- Of those who have been to a hospital appointment in the past **12** months (their own or a loved one's):
- **26%** say it takes them or a loved one the majority of the day to get to and from hospital.
- **15%** say they feel worse after hospital appointments than when they set out because of the stress involved in the journey.

As a society, we are failing those older people who can only reach their essential hospital appointments after a stressful and uncomfortable journey.

1. ILCUK/Age UK publication: The future of transport in an ageing society - 2015
2. Survey among 1342 people aged 65 or over - Travel to Hospital Appointments, TNS 2017



Our Call to Action

Age UK is calling on the Government to review transport services to ensure every older person can get to their hospital appointments within a reasonable time, in a comfortable, dignified and affordable way.



“To get to my nearest hospital, just five miles away, the bus is hourly and rarely fits in with the appointment. So I have to go two hours early, catch two buses, then walk or taxi the remainder of the way. An appointment there will take the entire day. I’ve refused appointments simply due to access.” **Rosina, 65**

KEY ISSUE ONE: LONG AND UNCOMFORTABLE PUBLIC TRANSPORT JOURNEYS

Many older people have no option but to rely on public transport to get to their hospital appointments. For some, this can mean difficult and uncomfortable journeys, involving multiple changes. These journeys are particularly difficult when older people are in very poor health.

Around 25% of bus journeys taken by older people aged 65+ are for medical appointments³ yet many struggle with inaccessible or irregular bus services. These journeys have been made increasingly difficult because of the number of bus routes which have been cut in recent years.

Even where buses do run to hospitals, bus stops can be located too far away from the hospital entrance. This makes it very difficult for older people with a disability or mobility issues to get to the hospital department they need.

Our survey among supporters found several instances where public transport issues had forced older people to cancel, refuse or miss their appointments altogether.

3. The costs and benefits of concessionary bus travel, Greener Journeys, September 2014

“I have to take three buses to get to my appointments – with the pain in my back and legs, I dread the journey to hospital.”

Subhash's story

Subhash, 69 has Parkinson's and diabetes. He has to go for regular hospital appointments to meet with his neurologist. When he tried to apply for patient transport, he was told he did not live within the hospital's catchment area.

Subhash is forced to take public transport to hospital. Because of his Parkinson's and difficulty with his eyes, it isn't safe for him to travel alone.

“I'm forced to rely on my wife to get to hospital. We have to take three buses to get to my appointments. It's a nightmare to change bus three times – it is very painful for me to walk, not just in my legs but also in my back. With the pain in my back and legs, I dread the journey to hospital.

It takes me two and a half hours to get to hospital via the three buses. So if I have an appointment at 10am, I have to leave the house at 7am.”



KEY ISSUE TWO: HOSPITAL-PROVIDED PATIENT TRANSPORT IS OF VARIABLE QUALITY

Older people may be eligible for free patient transport services if they have a disability or condition that makes it difficult or impossible to travel by public transport. Our research shows the service they receive is of very variable quality. Efficiency and timeliness are often far from guaranteed.

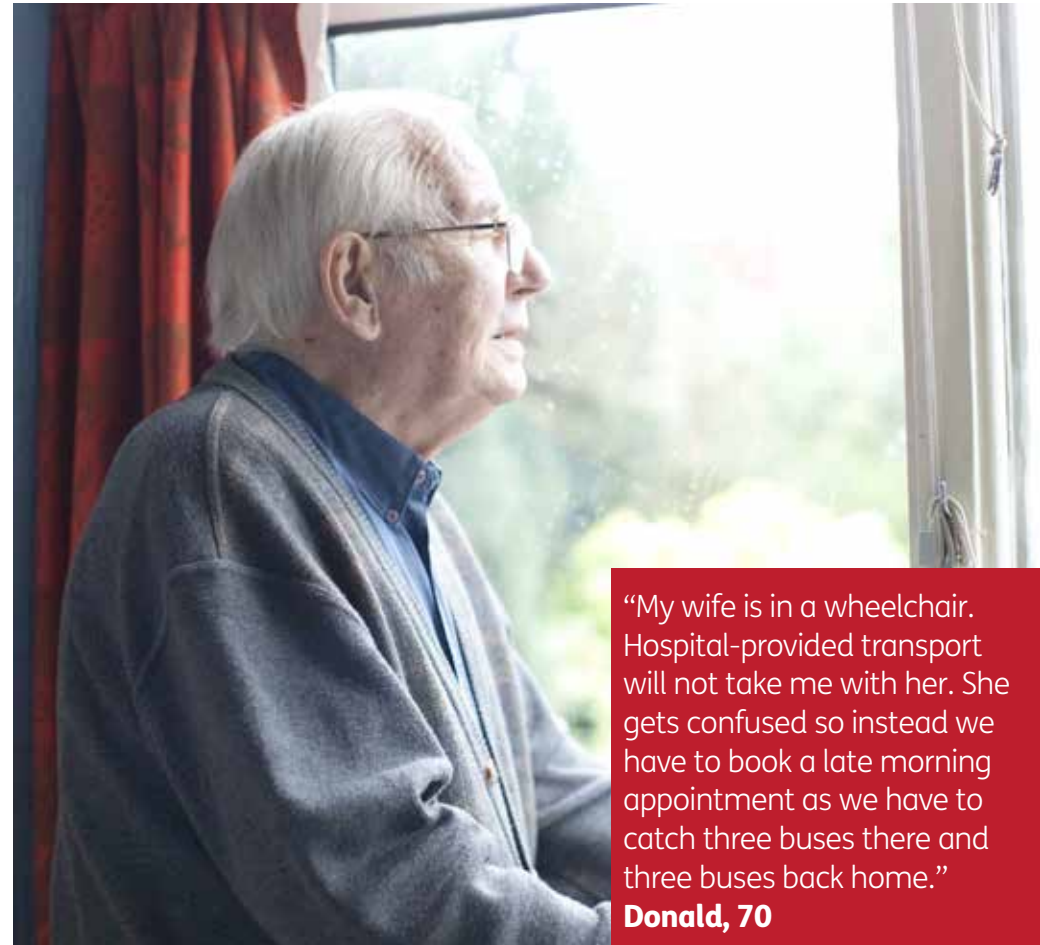
Transporting older people to and from hospital costs the NHS a lot of money. Yet who gets help and how good that help is seems to be something of a postcode lottery. Community transport providers and volunteers offer services to fill the gap in demand in some areas. However, they are not always formally linked in to transport commissioning processes, which means the provision isn't fully utilised and some older people don't even know it exists.

The most common problems reported are:

- Long waiting times – poorly co-ordinated services mean despite feeling very unwell, many older people are picked up hours before their appointment and left waiting for hours afterwards by themselves until they are picked up for their return journey.
- Patients may be unable to travel with a companion – for many older people, particularly those in a wheelchair, or living with dementia, travelling alone when they are in poor health is very distressing. Some older people are forced to make a difficult decision between a long and uncomfortable journey on public transport where they are at least able to travel with someone, or travelling alone in the hospital's patient transport service.



- Changes in eligibility – many reported that hospitals are tightening the criteria of who qualifies for free patient transport.
- Vehicles are not suitable – those with specific health needs often find the vehicle that arrives to pick them up isn't suitable for their needs. For instance, it won't fit their wheelchair.



“My wife is in a wheelchair. Hospital-provided transport will not take me with her. She gets confused so instead we have to book a late morning appointment as we have to catch three buses there and three buses back home.”

Donald, 70



“The chemotherapy itself is already so exhausting. But sometimes I have to wait for two hours afterwards to be picked up by hospital transport. It’s just too much.”

Connie’s story

Connie, 74 was diagnosed with breast cancer in 2000 and eventually given the all clear. But in 2009, the cancer came back. Now, nearly every week, she has to go to the hospital for chemotherapy.

“I can’t drive because the medication I am on gives me dizziness. I never leave the house for leisure, only to go to hospital. I qualify for hospital-provided transport because the side effects of my chemotherapy medication make it hard to walk, so I need a crutch.

One time they told me to be ready by 6am and didn’t arrive until 7:30am. I was so tired and stressed by the time I started, and the treatment is already so exhausting.

After you have finished your chemo, you just want to go home. But sometimes I have to wait two hours afterwards to be taken home. No one comes to see how I’m feeling. I wait on my own.

When I finally get picked up, it takes hours. I just want something that will take me directly home, so I can sleep. It’s just too much.”

What people have told us

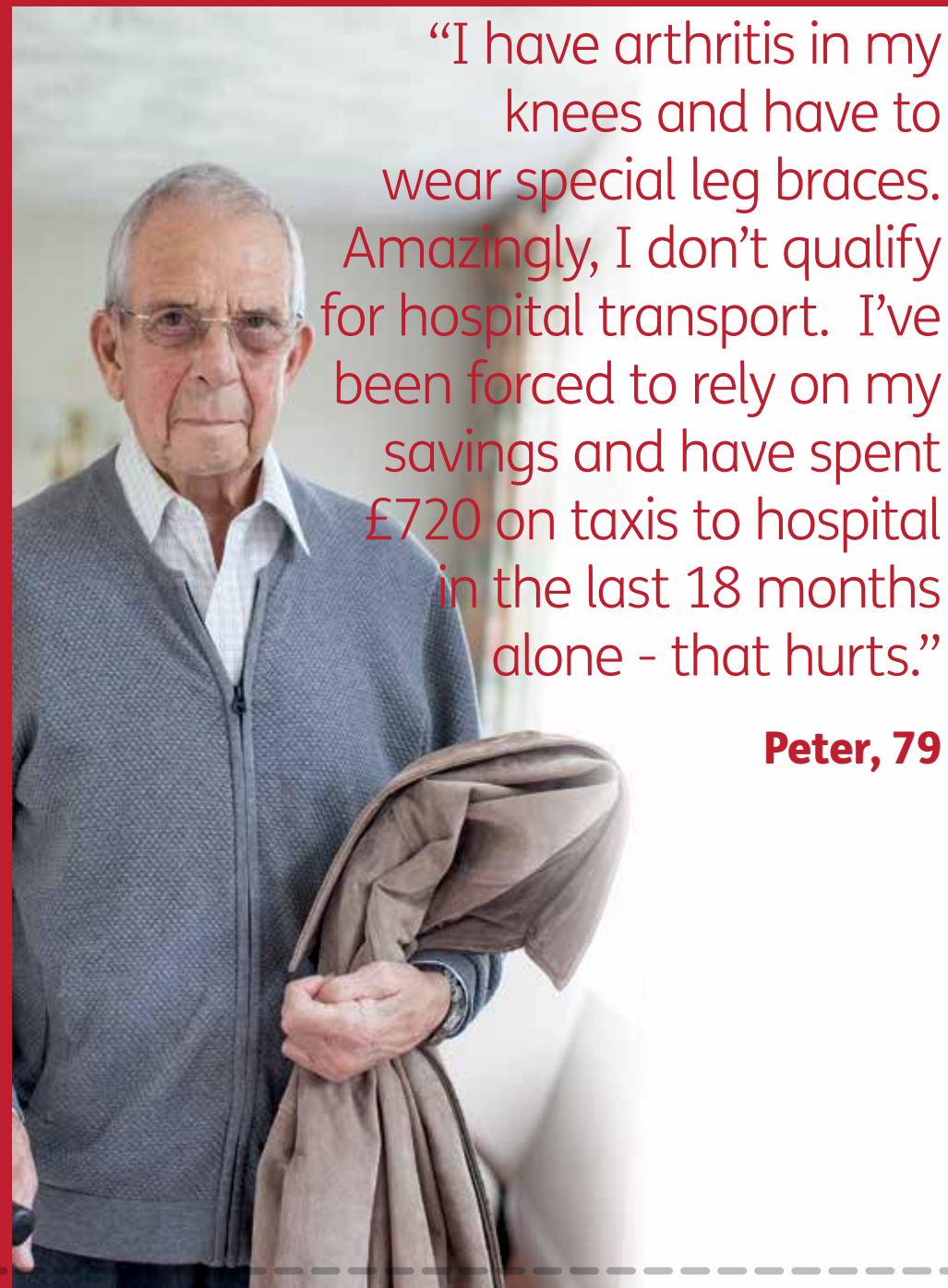
“On one occasion I phoned the community NHS ambulance scheme and was told to be ready by 9:30am. I waited and waited until at midday I eventually managed to get through on the phone again, only to be told the transport had been cancelled because they didn’t have a wheelchair. I was in tears.” **Pauline, Chiswick**

“My mother is 89. She had her hospital-provided transport cancelled at the last minute and lost her appointment the next day. She had to wait 6 weeks for another and again, the hospital provided transport didn’t turn up. We all found it extremely stressful.” **Mrs Bolland, Somerset**

“My husband is house bound and disabled. In order to get him to hospital I have to pay for a special taxi because if he goes by hospital transport I’m not allowed to go with him.” **Jill, Coventry**

“I waited one and a half hours for hospital transport home from a consultant’s appointment and the journey then took three hours instead of 25 minutes because they delivered other people home first.”
Alice, South West England

Some names have been changed.



“I have arthritis in my knees and have to wear special leg braces. Amazingly, I don’t qualify for hospital transport. I’ve been forced to rely on my savings and have spent £720 on taxis to hospital in the last 18 months alone - that hurts.”

Peter, 79

KEY ISSUE THREE: THE COST TO OLDER PEOPLE AND THEIR FAMILIES

As we get older, we all want to remain independent for as long as possible and not have to depend on others in order to do routine things. The bus pass is a valuable benefit that supports people to travel to hospital - but not when bus services have been cut or routes do not run close enough to hospital entrances. As a result, many older people are totally reliant on family or friends to drive them to hospital, even though they would much rather be able to get there under their own steam.

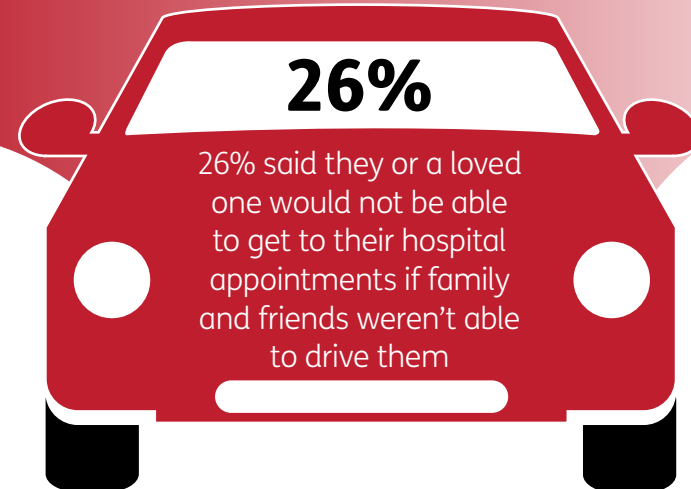
This has a significant impact on their families because they have to take time off work to accompany their relative to an appointment. Parking can also be difficult - charges can be high, and often there are no available parking spaces, or those that are available are not near enough to the entrance to the hospital.



Alternatively, older people have to use expensive taxis - often with drivers who are not trained to deal with people with health or mobility issues. For patients in wheelchairs, specialist vehicles need to be hired for each journey, sometimes at prohibitive cost.

“My Grandfather has to rely on taxis or lifts from family to get to hospital appointments on a regular basis. He is 88 with mobility issues. There is no hospital transport available for him and a taxi costs £30 return. The taxi drivers are not able to assist him to the main entrance or even help him in and out of the car.” **Emma, Sheffield.**

“There isn’t enough affordable parking near the hospital. Last time there wasn’t any parking within a two mile radius, we had to either walk or catch a cab with my 89 year old mother who has heart disease and lung cancer. As she lives nine miles from the hospital, if I didn’t drive her she would require a taxi, then two train journeys, then a bus and a 100 metre walk into the hospital.” **Justin, Croydon**





“Because I have no idea when she will be picked up or dropped off, I have to take the whole day off to look after her.”

Dorothy's story

Dorothy, 57 from Oldham has to take the whole day off work every time her mother Janet, 94 has to go into hospital.

“My Mum has vascular dementia, so it can be an absolute nightmare getting her to hospital. She qualifies for hospital-provided transport but we never get told an estimated time of arrival and often wait for two and a half hours.

No one enjoys hospital appointments, so imagine what it is like if you have dementia. You can't just leave her waiting in her coat for hours. When she gets confused and anxious, we both get upset.

Because I have no idea when she will be picked up or dropped off, I have to take the whole day off to look after her. I manage sheltered accommodation, so having to take a whole day off to look after Mum completely disrupts my shifts and the schedule of the vulnerable older people I look after.

‘I have tried booking a taxi but a special wheelchair taxi costs £40 a journey. I just can't afford that. The awful thing is, I only work 10 minutes away from my Mum - so if they let me know when they will arrive, I would only have to take an hour or two off work. This would be far less disruptive for me, and far less stressful for my Mum.’

Why we need a Government review

As a society, we need to make sure that every older person can get to their hospital appointment safely and straightforwardly, without being made to endure anxiety, exhaustion or distress. The current system is just not good enough:

- **People are late or missing appointments because they can't get there in time** – 16% report they or a loved one have been late or had to cancel an appointment because of difficulties getting there. This represents a significant cost to the NHS.
- **Difficult journeys are making people even more unwell** – defeating the purpose of them attending their hospital appointment in the first place. 18% report the journey to hospital makes them or a loved one feel stressed or anxious and 15% say they feel worse after returning from hospital appointments because of the stress of the journey.
- **Getting to hospital need not be an ordeal** – there are already parts of the country where older people can get to their appointments in a straightforward way. For instance, some areas work in partnership with Local Authorities to use their transport commissioning expertise or make intelligent use of community transport services and volunteers.



Age UK is calling on the Government to conduct a review of transport services to ensure every hospital journey for an older person:

- Is reasonably comfortable
- Is reasonably affordable
- Keeps stress and anxiety to an absolute minimum, and
- Gets them to and from hospital in good time, without long waits.

Age UK

Tavis House

1-6 Tavistock Square

London WC1H 9NA

www.ageuk.org.uk/painfuljourneys

Email us: campaigns@ageuk.org.uk

Age UK is a charitable company limited by guarantee and registered in England and Wales (registered charity number 1128267 and registered company number 6825798. Registered address: Tavis House, 1-6 Tavistock Square, London WC1H 9NA. Age UK and its subsidiary companies and charities form the Age UK Group, dedicated to helping more people love later life.