



**IN-DEPTH POLICY REPORT**

# 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 the journey alone, in chronic pain and having to take three different buses to get there. This is the reality for many of the older people we have heard from.

That's why Age UK is calling on the Government to urgently review the way older people travel to their hospital appointments.

This report outlines how poor and inadequate transport options impact on older people travelling to hospital for non-emergency medical treatment. We also propose a series of ideas for how the system could work better.

The issues we raise and the ideas we propose are based on:

- focus group discussions with older people's groups in Newcastle and Falmouth<sup>1</sup>, which particularly highlighted the differences between rural and urban transport.
- Data from a nationally representative survey conducted by TNS for Age UK among over 1300 people aged 65 and over in G.B.<sup>2</sup>
- Case studies from our information and advice service<sup>3</sup>, and
- Responses to a survey among our supporters<sup>4</sup> which illustrate some of the typical problems experienced by older people travelling to hospital appointments.

Research carried out by the International Longevity Centre (ILC) for Age UK found that **1.45 million people over 65 find it quite difficult or very difficult to travel to a hospital**. However, there appears to be considerable variation in how easy or difficult it is to get to a hospital depending on where you live.

Understandably the emphasis is often placed on the efficiency of the ambulance service in responding to emergencies or urgent cases. But there is less attention given to the day-to-day travel difficulties of older people getting to routine treatment who don't qualify for patient transport services. Regular medical treatment, including dental and eye checks, clearly lowers the risk of unplanned emergency medical interventions.

1. Thank you to all those who took part in the focus groups and contributed their thoughts, ideas and experience to this report.

2. Survey among 1342 People aged 65 and over – Travel to Hospital Appointments, TNS 2017

3. Many thanks to Richard Kitch (Age UK) for supplying inquiry details.

4. Survey among 3,680 Age UK supporters, August/September 2017

There is widespread consensus that the NHS must do more to reduce emergency admissions by older people whose health has deteriorated to a crisis point. The Department of Health believes part of the solution is to take an 'integrated approach' to the delivery of health and social care as part of the NHS Sustainability and Transformation Plans (STP). However, transport is still one of the fundamental aspects that is often overlooked in getting older people to medical services for treatment.

## Key issues

There are three main issues which we have identified as key problems for older people's transport to hospital:

- Long and uncomfortable public transport journeys
- Hospital-provided patient transport
- The cost to older people and their families

## KEY ISSUE ONE

### Long and uncomfortable public transport journeys

#### A. Cuts to bus services

Around 25% of bus journeys taken by people aged 65+ are for medical appointments<sup>5</sup> but many struggle with poor, inaccessible, uncomfortable or irregular services. Clearly, buses provide an important and affordable way for older people to get to medical and healthcare services if they do not qualify for patient transport services. However, cuts in services may leave them with limited or costly transport options. The Campaign for Better Transport found that supported bus services in England have been cut by £73.8 million since 2010/11, a reduction of 25 per cent.<sup>6</sup> They also found that 500 routes were reduced or completely withdrawn in 2016/17.<sup>7</sup>

Cuts not only impact on rural communities where older people often struggle to get to their local hospital, but also affect those in urban areas. Our survey people aged 65+ found that almost a quarter (24%) felt there was no form of public transport which would get them or a loved one to their hospital appointments on time.

5. The costs and benefits of concessionary bus travel, Greener Journeys, Sept 2014 – Populus survey 'Health benefits of bus travel' <http://www.greenerjourneys.com/wp-content/uploads/2014/09/Concessionary-travel-costs-and-benefits-September-2014.pdf>

6. Buses in Crisis A report on bus funding across England and Wales 2010 – 2016. Available online at: <http://www.bettertransport.org.uk/sites/default/files/research-files/buses-in-crisis-2015.pdf>

7. <http://www.bettertransport.org.uk/buses-crisis-2017>



**As a recent study among over 60's reports<sup>8</sup>, (UCL Institute of Education, reported in the BMJ in September 2017), improving the quality of, and access to public transport may help prevent future health problems among older adults and help maintain their physical capabilities.**

Although buses are more frequent in urban areas they can still be affected by poor access, overcrowding, and badly located routes and stops.

In places where buses have been cut, local communities are often told it is because they are no longer commercially viable. A failure to maintain rural bus routes has long term social and economic costs which are then transferred to the NHS or the care system later on. This is because older people unable to receive preventative medical care or remain socially engaged are much more likely to end up in hospital or residential care because they can no longer live independently. Although there are many other factors that contribute to this, access to public transport is an important component.

The alternatives to a regular bus service will depend on the arrangements made between the local authority, the NHS and the community transport sector – which will vary from place to place. However, some local authorities do not feel they are under any obligation to consider the alternatives when a bus route is cut. There is hope that the Bus Services Act 2017 will improve the situation for selected local authorities with an elected mayor<sup>9</sup>. New transport partnerships and franchising powers could help to fill gaps in services which affect vulnerable groups. Although the legislation offers the opportunity for more integrated services, many rural places will not benefit from the additional powers unless they are extended to more local authorities.

#### ● **SUPPORTER SURVEY**

##### NO BUS SERVICE OR AN UNRELIABLE SERVICE

“There is no public transport to any of the hospitals. My family can help occasionally but they are all working. My husband can drive but he has had two cataract operations this year and this was a problem. Also I am in a wheelchair so my husband has to push me. He's nearly 83 so I'm concerned about him now.”

Where buses are running, there may still be problems with regularity and reliability. Bus services are often given a low priority, with a failure to implement basic measures that can ease delays - such as dedicated bus lanes. Older people who need to get to a hospital appointment by a specific time must have public transport that is consistent and reliable.

When appointments are missed they are not only costly to the health of the individual but also have financial implications for the NHS. It is

8. <http://bmjopen.bmj.com/content/7/9/e017702>

9. <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7545#fullreport>

estimated that missed GP and hospital appointments cost the health service £1bn a year<sup>10</sup>. **Age UK would like to see further research to determine the number of missed appointments related to public transport delays or failures and measures to alleviate the problem.**

The journey to a hospital may involve having to change buses or travelling by train. A lack of connectivity between different operators can make it very difficult to plan a journey to hospital. For older people with restricted mobility or a disability who do not qualify for hospital transport, the journey can be lengthy, difficult and uncomfortable.

## **B. Poor bus accessibility**

A Lords Select Committee report<sup>11</sup> on the Equality Act 2010 noted that despite progress there was a lack of monitoring and enforcement to ensure older and disabled people are able to use public transport in different places. Age UK set out its own concerns on accessible bus services in its submission to the Transport Select Committee during the passage of the Bus Services Act 2017.<sup>12</sup>

Older people may qualify for a bus pass but they may still struggle to actually get to a bus stop. **Around 35,000 people aged 65-84 in England have difficulty walking even a short distance, but have no choice but to use public transport<sup>13</sup>.**

Bus stops can be badly located and involve crossing busy traffic and having to step over high kerbs or other obstacles. At the stop, the lack of a bus shelter or seating can add to the general discomfort of waiting.

If a bus shelter is located too far away from the hospital entrance or at the bottom of a steep hill it can make life unnecessarily difficult for older people. Planners do not always ensure that bus stops are located close to hospitals and other medical services.

Age UK believes that, particularly in rural areas, public transport should be designed around access to hospitals and other essential services. Hospital trusts must engage with local authorities and transport operators about getting older people to their services.

10. <http://www.bbc.co.uk/news/uk-33375976>

11. <https://www.publications.parliament.uk/pa/ld201516/ldselect/ldselect/117/117.pdf>

12. <https://www.publications.parliament.uk/pa/cm201617/cmpublic/bus%20services/memo/bsb06.htm>

13. [http://www.ilcuk.org.uk/index.php/publications/publication\\_details/the\\_future\\_of\\_transport\\_in\\_an\\_ageing\\_society](http://www.ilcuk.org.uk/index.php/publications/publication_details/the_future_of_transport_in_an_ageing_society)



### ● FOCUS GROUP

#### STOPPING NEAR THE HOSPITAL ENTRANCE

“Most of the buses here don’t go directly to the hospital. They stop at a lay-by which makes it difficult if you have problems with walking. It means you have to get across a busy main road.”

“You can get a bus and it takes you to the front of the outpatients - but the bus does not go all the way to the radiotherapy centre for cancer patients. That means patients have to walk three quarters of a mile to get there, which is not helpful if you’re not very well.”

“Public transport never really goes right up to the hospital entrance - it goes to a stop on the road nearby. A few services go right up to the door - but it depends on the hospital you attend.”

### ● SUPPORTER SURVEY

#### POORLY LOCATED BUS STOPS

“I have to walk too far as there is no stop near the hospital outpatients.”

The attitude of the bus driver to older people can also be an important factor. It can be particularly painful and stressful for older people if a bus is driven with lots of sharp stops and starts. It can be a problem if the bus does not stop at the correct alighting space or the driver fails to lower the floor of the bus to make it easier to step on.

### ● FOCUS GROUP

#### WHEELCHAIR SPACE ON THE BUS

“The driver said I couldn’t get on because there was a push chair in the wheelchair space. I said ‘can’t you ask them to move it?’ He said ‘No - they have priority because they got here first’. People on the bus were going crazy saying - ‘Let him on the bus!’”

A recent appeal to the Supreme Court<sup>14</sup> considered the role of the bus driver in a dispute over the use of wheelchair space to store pushchairs. It was determined that a bus driver must give priority to a wheelchair user and put pressure on a non-wheelchair user to vacate the space, depending on the circumstances. Age UK believes the priority for wheelchair users should be strongly enforced - but in the longer term we would like to see buses that accommodate both wheelchairs and buggies to avoid conflict. If a bus

cannot accommodate a wheelchair user, for whatever reason, there should be an obligation on the bus company to pay for a taxi to take them to their destination. The Brighton & Hove Bus & Coach Company & Metrobus have already developed such a scheme if passengers refuse to clear a space for a wheelchair user<sup>15</sup>.

More generally the approach and training of the driver is an important factor in encouraging older people to use the bus. A negative, impatient or unhelpful attitude from the driver or other passengers towards older people can be stressful and upsetting and can put them off using the bus. Our focus group said that if a driver was rude or unpleasant it could ruin their day – but a friendly driver made them feel more positive and confident.

The Government have consulted on the introduction of disability awareness training for bus drivers, although a number of companies say they already offer this form of training. Despite examples of good practice, this is inconsistent across different bus operators. Issues around the delays caused by older and disabled people struggling to get on and off the bus could potentially be solved by improvements in bus design and support from transport staff with an awareness of disability and the needs of older people.

There are already a number of local authorities and operators who actively promote the accessibility of their local bus services to encourage older and disabled people to use them. We have seen initiatives in London, Oxfordshire, and Brighton and Hove as well as broader participation in the annual ‘Catch the Bus’ week, which profiles the positive benefits of bus travel<sup>16</sup>. Proactive approaches can help to address some of the negative assumptions that older people may have about using public transport to get to an appointment. However, there needs to be a more consistent approach towards accessibility across all local authorities.

## ● CASE STUDY

### PAIN WHEN USING PUBLIC TRANSPORT

Liz is a carer for her husband Sam who has multiple health problems and is awaiting surgery for an abdominal condition. Part of Sam’s treatment involves radiotherapy for prostate cancer. Liz is finding it difficult to cope with traveling with Sam to hospital appointments because they have no car. Using public transport can take several hours out of the day. Because Sam is in constant pain he struggles with public transport which involves taking two buses there and back.

14. <https://www.supremecourt.uk/cases/docs/uksc-2015-0025-press-summary.pdf>

15. <http://www.transportforall.org.uk/news/what-are-bus-companies-doing-to-improve-access-for-disabled-and-older-people->



## C. Bus pass restrictions

Many older people value the free bus pass<sup>17</sup>. Having a bus pass helps to keep older people active and socially engaged, which in itself benefits their overall health and wellbeing. However, the usefulness of a bus pass can depend on where you live. In some places the bus pass can provide free or discounted travel on certain types of community transport - but this depends on the agreement with individual local authorities and health commissioners.

A difficulty raised by the older people we've spoken to is the cost of transport for people with mobility problems who have not yet reached the qualifying age for a bus pass or do not qualify for a disabled person's bus pass. The qualifying age is based on the State Pension age - although some local authorities offer more generous schemes. If older people do not yet qualify for a pass or no buses are available to take them to hospital the alternatives can be expensive.

### ● CASE STUDY

#### IF YOU DON'T QUALIFY FOR A BUS PASS

Marion is 62 years-old and suffers with rheumatoid arthritis, requiring frequent visits to hospitals and other appointments. Marion doesn't qualify for a bus pass and pays £3.80 each visit - which soon adds up.

### ● CASE STUDY

#### UNABLE TO USE A BUS PASS

Ken's mum Carol has lymphoedema and goes to a clinic for treatment. She is not entitled to free transport to the clinic. She cannot use her bus pass because the buses don't go there. Ken wants advice on his mum's options to get to appointments and receive the treatment she needs.

Restrictions imposed by some operators and local authorities on the time of day that bus passes can be used mean that morning hospital appointments are unsuitable as they can be expensive if full fares need to be paid.

16. <http://www.catchthebusweek.co.uk/partners>

17. <http://www.ageuk.org.uk/money-matters/claiming-benefits/public-transport-and-concessions/transport-concessions-older-people/>



## ● SUPPORTER SURVEY

### BUS PASS VALIDITY

“I can’t travel on my own and it’s often hard to get someone to accompany me. My bus pass is not valid until 9.30am and once my appointment was 7am. When I told the hospital they said that 7am was the only time available. Every time I ask for transport they say they don’t provide it and I have to get my own.”

## D. Companion travel on public transport

Older people with restricted mobility may need some help getting on and off the bus and a GP may advise them to travel with a companion who can offer support and assistance, especially if they live on their own. It can also be helpful in the short term for older people who lack the confidence to use a bus to get to hospital - perhaps for the first time.

Some local authorities allow someone to accompany a disabled person on the bus at a free or discounted rate. However, these companion assistance schemes (sometimes known as plus one schemes) are not mandatory and the qualifying criteria may vary between different local authorities<sup>18</sup>. In some places these schemes are not available at all.

Our focus group discussion indicated that the criteria for companion travel needs to be more flexible.

## ● FOCUS GROUP

### ENTITLEMENT TO COMPANION TRAVEL

“They said to me if you can get on a bus on your own you are not entitled to a companion card, even though I’m blind.”

In this comment from our focus group the participant explained that when he took a bus journey that was unfamiliar to him he needed some help, but was told he did not qualify under the local companion assistance scheme. He said he only needed help on the first few journeys so that he could become familiar with the route. This perhaps indicates the need for a clear and consistent national scheme that supports older people who have just started making the journey to hospital by public transport for the first time and perhaps feel nervous or uncertain.



Local authorities have discretion over companion travel for a partner, relative, friends or volunteer. The ability to obtain assistance can have an impact on an older person's confidence to travel to hospital by public transport. Isolated older people living alone may be reluctant to use public transport simply because they are unable to find assistance.

## **E. Lack of awareness of local transport options**

Older people may know about local bus services but be unaware of community transport and other options. **A number of voluntary agencies and older people's groups have developed directories of community transport services. These can be fantastic resources but GP's and hospitals still need to proactively communicate information on what is locally available to older patients who may not be aware of this information.**

During our focus group discussions some participants only became aware of local transport options when the information was shared within the group. Older people often find out about what is available through a local Age UK, lunch club or day centre.

An important aspect of the Bus Services Act 2017 is that it will allow more information from different buses operators to be available in one place both online or through a smart phone app. This will make planning journeys easier and result in better connected services. However, there are still many older people who are not online or do not use a smart phone - so will not directly benefit. It is important that when this information becomes available it is provided in accessible formats designed for all older people.

While there are some voluntary groups that work with local authorities there needs to be a more consistent approach to distributing offline information, particularly to hard to reach groups.

### **● FOCUS GROUP**

#### GETTING INFORMATION ABOUT HOSPITAL TRANSPORT

"We didn't know there was a printed list of community transport services for this area available from the library. But you still need transport to get to the library."

"The only reason I knew how to get help to get to the hospital was because my neighbour told me."

18. <http://www.nottinghampost.com/89-year-old-woman-denied-companion-bus-pass-despite-being-wheelchair-bound/story-29855424-detail/story.html>

One of our focus groups told us that in their area the patient transport service uses taxis, but not everyone in the group was aware of this. It appears that in some places information on help with travel is not routinely offered to all older patients. Local Age UKs regularly receive inquiries concerning help with travel costs which older people might reasonably expect to get from their GP or local hospital.

### ● CASE STUDY

#### SEEKING HELP WITH COSTS

Helen's mum Eileen has breast cancer but her dad Jim is struggling to get her to hospital for all of her treatments. They cannot afford to pay for transport each time. Helen lives many miles away and works full-time so is unable to offer consistent help. Helen is unsure whether they qualify for any assistance to help them with transport costs.

In this case the hospital or GP should have discussed with Eileen and Jim whether they qualified for help with transport and if not examined the alternatives such as community transport services.

## F. Underfunding of community transport services

The term 'community transport' refers to many forms of transport, such as minibuses, dial-a-ride services or volunteer driver schemes, all of which are likely to be organised locally and based on local need. Community transport can take older people from door-to-door and offer additional assistance which is unavailable from public transport.

A high proportion of its passengers are older people travelling to hospital appointments, often because of a lack of public transport. Despite this many community schemes experience ongoing funding problems, although the Government has made some funding available to purchase vehicles.<sup>19</sup> Community transport may not receive the same subsidies as commercial services despite the fact they may be filling in a gap in commercial routes, especially in rural areas.

In some local authorities older people can use their bus pass to get free or discounted community transport. It can be argued that there should be greater flexibility to allow all older people to use their bus pass for community transport, especially in areas where there is no bus service available.



The Community Transport Association (CTA) argues that local community transport providers can be excluded from the local commissioning of services despite their vast experience of providing non-emergency transport to hospitals and GPs<sup>20</sup>. This seems to indicate a lack of strategic thinking in some places about how different parts of the local transport system can work together to offer a better service to older and disabled people. **However, in some places hospital trusts collaborate with community transport services to schedule appointments in order to increase the number of patients able for travel to similar treatment and reduce waiting times.**

Volunteer driver schemes offer a door-to-door service, and can provide an affordable and trusted alternative to a taxi. They also offer additional support and assistance to help older people get from the vehicle to inside the hospital. However, they are not available everywhere and rely on funding and the ability to recruit volunteers.

#### ● SUPPORTER SURVEY

##### VOLUNTEER CAR SCHEMES

“We rely on volunteer car services, one of which has just ceased operation. Our nearest hospital is 22 miles away and the main hospitals are 50 and 60 miles away.”

This could be improved by GPs and hospitals improving communication with the scheme managers. Where they do not exist older people still need to be offered alternatives such as discounted taxis.

#### ● CASE STUDY

##### ROLE OF VOLUNTEER DRIVER SCHEMES

Margaret contacted us hoping to find a driver scheme in her area. Her 96-year old dad has Alzheimer’s disease and profound hearing loss. Tracey lives two hours drive away from him. Although she was able to take him to a Memory Clinic appointment she was unable to take him to a hearing test appointment later in the week 2 days later.

19. Available online at: <https://www.gov.uk/government/news/2-million-available-for-community-minibuses>

20. Available online at: <http://www.ctauk.org/UserFiles/Documents/In%20Your%20Area/England/State%20of%20the%20Sector%20for%20inhouse%20print.pdf>

## KEY ISSUE TWO

# Hospital-provided patient transport

### A. Tightening of eligibility

If you are a non-emergency patient you are often expected to make your own way to hospital. However, older people may be eligible for free patient transport services<sup>21</sup> if they have a condition or disability that makes it difficult or impossible to use public transport. However, there are often variations in the quality of patient transport services in different places and the criteria to qualify for help have been tightened<sup>22</sup>. The outsourcing of patient transport has contributed to poor and fragmented services in some places<sup>23</sup>.

#### ● FOCUS GROUP

##### ENTITLEMENT TO PATIENT TRANSPORT

“People think they are entitled to patient transport because they use a wheelchair, have difficulty walking or have a heart condition - but I’ve been refused twice. I’ve had heart failure, a heart operation and I’m mostly in a wheelchair so I’m not sure why they refused me. I had no choice but to get a taxi and it costs £28 for a short journey.”

#### ● SUPPORTER SURVEY

##### ENTITLEMENT TO PATIENT TRANSPORT

“I have to get to a hospital 20 miles away every 1 or 2 weeks. I drive very little now due to epileptic fits. I am unable to get an ambulance as I don’t fulfil the criteria, so I have to pay for a taxi ... I also have to attend another hospital 8 miles away via 2 buses, but due to traffic problems on the bus route, have to get a taxi there. It costs us a bomb!”

#### ● CASE STUDY

##### PATIENT TRANSPORT UNAVAILABLE

Rosemary is over 80 and does not drive any more. She has to attend the main hospital and has been told that as she does not need a wheelchair for her restricted mobility no outpatient transport is available to her. She will have to pay for a private taxi for appointments.

21. <http://www.nhs.uk/cha/Pages/1079.aspx?CategoryID=68>

22. [http://www.economist.com/blogs/blighty/2011/04/patient\\_transport](http://www.economist.com/blogs/blighty/2011/04/patient_transport)

23. <https://www.unison.org.uk/content/uploads/2017/04/Patient-Transport-Services-report.pdf>



Older people may also be able to claim a refund for travel expenses through the Healthcare Travel Costs Scheme<sup>24</sup>. This is means tested and available to patients unable to pay for transport themselves. However, older people may not know about this, be embarrassed to claim, or encounter problems with reimbursement on the day or for payment in advance as well as overly bureaucratic systems that create difficulties for them.

## **B. Long waiting times for collection and return**

One of the most frequently mentioned problems which has emerged from our research is that of long waiting times for collection and return from hospital appointments. Patients are routinely asked to be ready for pick-up 2 hours or more before the collection time they are given, and are often not delivered back home for many hours after their appointment.

### **● CASE STUDY**

#### **LONG WAITING TIMES FOR HOSPITAL TRANSPORT**

“I use the hospital transport service to get to appointments. One time they told me I had to be at the hospital at 8am, and that I had to be ready to be picked up by 6am. In the end they didn’t arrive until 7.30am. It meant I was already tired by the time I had to go for chemotherapy, and the treatment itself is so exhausting. Sometimes I would have to wait two hours afterwards, and then when I finally got picked up, they have to drive all around the borough to drop everyone off. I just wanted something that would take me directly home so I could sleep.”

For people in wheelchairs, waiting for hours for their appointments can be painful and embarrassing – toilets may be difficult to access which leads to additional anxiety and distress for the patient:

### **● CASE STUDY**

#### **WHEELCHAIR USER**

“There was a problem that delayed my appointment and my driver had to leave and I had to wait for somebody else to collect me. I left home at 11.30am and got home at 8.30pm, which was a big problem as the disabled toilet was far too small for my chair.”  
Maureen, 74

24. <http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx>

## ● FOCUS GROUP

### DIFFICULTIES WITH HOSPITAL TRANSPORT

“I need help to get to hospital because I’m a wheelchair user. They send the ambulance really early and you are in it for two hours because they have to pick up two or three other people. When you get there it’s often well past your appointment time even though the hospital knows it takes time to get you there. I’ve now stopped using this service.”

“We use hospital transport but after 2 or 3 times we gave up because we just couldn’t cope with it.”

“You really have to plan ahead if you are going to get to your appointment in good time. Some services require a week’s notice and need to call you back to confirm they can get you there - which can be stressful.”

“If you’ve got an appointment early in the day the chances of getting there on time by hospital transport are pretty minimal. When you’ve finished your appointment you’ve just got to wait to be picked up because it’s not just you using it. You’ve got to be patient to be a patient!”

The inefficiency of some patient transport services has made some older people so frustrated they feel forced to use other forms of transport with additional costs they cannot really afford.

## C. Companion travel – hospital transport

Patients using hospital transport may be unable to travel with a companion and 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 are forced to make the 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.

Our supporter survey indicated that there is variation in the rules allowing a companion to accompany a patient travelling by hospital transport:



### ● FOCUS GROUP

#### COMPANION TRAVEL IN HOSPITAL TRANSPORT

“One time, travelling to hospital by patient transport, they had changed transport companies, and I said to the original company, ‘Make sure the carer – that is myself – is down to go with her. Because she can’t see or hear or walk very well.’ So the new company turned up and they said I couldn’t go in it. So I said – ‘what do you mean, I can’t go in it? It’s been booked and I have a reference number’. And they said – that was the previous transport company. So I said ‘I have to go in’. So I went in. And I sat down, and said ‘well she can’t go on her own’ and the driver went mad and kept making phone calls and eventually he said I could come along. But it was very traumatic.”

### ● SUPPORTER SURVEY

#### TRAVELLING WITH PATIENT IN PATIENT TRANSPORT

“My husband is housebound 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.”

### ● SUPPORTER SURVEY

#### TRAVELLING WITH PATIENT IN HOSPITAL TRANSPORT

“My husband has to go without me because I’m not allowed to travel with him in the hospital ambulance.”

### ● SUPPORTER SURVEY

#### TRAVELLING WITH PATIENT IN HOSPITAL TRANSPORT

“I am 70 years old and my wife is in a wheelchair, hospital transport will not take me with her. We have to catch three buses there and three buses back home.”

## KEY ISSUE 3

### The cost to older people and their families

#### A. Long journeys for specialist treatment

In many cases travelling a long distance to receive specialist treatment is unavoidable. However, a decline in local specialist clinics mean that



more older people have to travel for treatment outside their area, consequently an older person may not have access to a hospital-provided patient transport scheme. As this is becoming increasingly common, the Department of Health needs to investigate how hospital trusts can cooperate more effectively to join up patient transport. There is a need for clarity about who has responsibility for addressing the gap in transport services that get older people to hospital.

### ● CASE STUDY

#### RESTRICTIONS ON OUT OF AREA TRAVEL TO HOSPITAL

Joan's mum Sally was referred to hospital in another county for specialist treatment. Sally is wheelchair bound so Joan is exploring how Sally can travel to her appointment. Sally's doctor checked to see if she could use the local CCG hospital transport scheme. However Sally was told that because her appointment is 'out of area' this will not be possible. Joan wants to see if she can challenge the NHS to give access to alternative transport. Getting to the appointments by taxi would be too expensive.

### ● CASE STUDY

#### LONG JOURNEYS FOR SPECIALIST HELP

Terry needs complicated heart surgery, so is being referred to a hospital as one of only two places in the country can provide the operation he needs. It will require a long journey and an overnight stay, on several occasions. Terry ask if he can get any help with those costs. Terry's local council told him they could not help.

For some journeys for specialist treatment, trains could offer the quickest and easiest way to get to services. However, we know<sup>25</sup> that disabled older people often have severe difficulties using trains related to a lack of accessible toilets, difficulties getting on and off the train and a lack of staff to offer assistance. This means they can be excluded from using rail and have to find alternative ways to get to an appointment.

## **B. Older drivers and the problems with driving to hospital**

Some older people feel they have little choice but to drive to get to hospital. Older people are often reluctant to give up their car because they know the alternatives can be difficult and unreliable. A car or taxi journey



has the advantage of taking someone from door-to-door without the inconvenience of public transport. However, driving is not a safe option if for example their sight is affected, or they have been advised not to use machinery for a while after their treatment.

During our focus group discussion one person told us that although her husband could drive her to the hospital he could only do this ‘when he felt up to it’ and only at certain times of the day when there was good daylight. Many older people struggle with driving, especially at night, and therefore arrival and departure times from an appointment are important. It may also be problematic if an older driver has to take a long or unfamiliar route to get to an appointment.

### ● SUPPORTER SURVEY

#### DRIVING TO HOSPITAL

“I don’t like driving but have had to drive my husband to and from hospital, which is stressful.”

“I was so overcome by anxiety at the thought of driving to another county that I cancelled my appointment altogether.”

### ● CASE STUDY

#### FEARS ABOUT DRIVING TO HOSPITAL

Steve is a 63 year old registered disabled person. He drives locally but hasn’t driven on motorways for over 25 years. He now has several hospital appointments but these are 200 miles away. He found that he was not entitled to hospital transport or taxi token service. He is unable to pay for a taxi himself and believes he would be unsafe driving his old car that distance.

There are schemes that allow older people to check and improve their driving skills if they or their relatives have concerns. There is also help for older people through driver mobility centres<sup>26</sup> where a car can be adapted for a disability and older people are helped to retain their ability to drive safely for as long as possible. Where mobility centres have good links with hospitals they can give advice to older patients who are experiencing difficulties getting to appointments.

25. <http://www.papworthtrust.org.uk/sites/default/files/Improving%20rail%20travel%20for%20disabled%20passengers%20in%20Britain.pdf>

## C. Hospital Parking

A major concern with driving to hospital as a patient, carer or visitor, is parking. Our survey results highlighted not only the difficulties that drivers face finding a convenient parking space, but also the cost of parking.

### ● SUPPORTER SURVEY

#### PARKING DIFFICULTIES AT HOSPITAL

“Car parking is a huge problem. It takes too long by public transport so I have to drive. Parking spaces are very limited and I am often late due to parking issues.”

Some hospitals offer free or discounted parking for specific types of treatment and for those claiming certain welfare benefits. The Government has also issued guidance to hospitals on parking policies and concessions<sup>27</sup>. However, this guidance does not have legislative weight and there appears to be significant variation in parking fees across different hospital trusts.

### ● FOCUS GROUP

#### COST OF PARKING

“Something that worries everybody is hospital parking charges. If you have a relative taking you to the hospital you may have to wait 4 hours. Parking fees can cost a lot of money on top of the expense of getting there. There are alternatives but it would take you all day to get there and back.”

### ● SUPPORTER SURVEY

#### LACK OF PARKING SPACES AND COST OF HOSPITAL PARKING

“The main problem is the lack of parking. You have to drive round and round, and when you do find a place, my local hospital charges £3.50 for 2 hrs which goes up to £8 if it is over 4 hours. If you only pay for 2 hours and the appointment runs over, which often happens, you risk getting clamped.”

Many older people contacting Age UK often tell us about the difficulties of applying for blue badge parking and insufficient hospital parking spaces for disabled people. We have been told of some patients having to cancel their appointments because hospital car parks were full and disabled passengers could not walk from the car to their appointments.

26. <https://www.drivingmobility.org.uk/>



### ● SUPPORTER SURVEY

#### RESTRICTIONS BLUE BADGE PARKING SCHEME

“Parking arrangements for the disabled at my local hospital are unrealistic as they provide only a limited number of disabled bays, and patients are not allowed to use their Blue Badges in other sections of the car park.”

### ● SUPPORTER SURVEY

#### RESTRICTIONS BLUE BADGE PARKING SCHEME

“Parking near the clinic is difficult without a disabled parking badge and these are no longer available for people who are elderly with dementia but can walk 50m. I have to drop my mum off but I am worried she will wander off and get lost while I park.”

## D. Reliance on family and friends

Some older people rely on friends and relatives to drive them to hospital and in many cases this makes them feel a burden.

In our focus group one person told us that although she was able to get a lift from her daughter to get to hospital it was inconvenient because her daughter had to take time off from work. Although she was extremely grateful to her daughter she did not want to impose on her. She said having to completely rely on somebody else for a lift reduced her sense of independence.

### ● SUPPORTER SURVEY

#### DEPENDENCE ON OTHERS TO GET TO APPOINTMENTS

“I had to ring three people before I could find a friend who was able to take us. I feel bad having to ask people.”

The strain which this places on family members, some of whom are unwell themselves, is enormous:

### ● SUPPORTER SURVEY RESPONSE

#### STRAIN ON FAMILIES

“In one week I had to take my 78 year old dad, who has terminal

27. <https://www.gov.uk/government/publications/nhs-patient-visitor-and-staff-car-parking-principles/nhs-patient-visitor-and-staff-car-parking-principles>

cancer and COPD, to three different hospitals. I am a disabled driver and I struggled to drive him that week because each hospital was in a different town and the total mileage covered on hospital appointments was about 150 miles.”

## E. High cost of privately-hired taxis

Where patients do not have family or friends able to drive them, their only alternative is to hire taxis, which many older people find difficult to afford on a regular basis.

### ● SUPPORTER SURVEY

HIGH COSTS FOR PRIVATE TAXI

“I couldn’t afford a taxi, so I had to cancel my appointment.”

If they need a vehicle with wheelchair access, the cost of this can be prohibitive for some families, who then need to rely on alternative transport:

### ● CASE STUDY

HIGH COSTS FOR VEHICLE HIRE WITH WHEELCHAIR ACCESS

“I have tried booking a taxi (for my mum) but a special wheelchair taxi costs £40 a journey. I just can’t afford that.”

### ● SUPPORTER SURVEY RESPONSE

HIGH COSTS FOR VEHICLE HIRE WITH WHEELCHAIR ACCESS

“Taxi companies here don’t let you pre-book vehicles with wheelchair access because they are freelance drivers. We don’t want to run the risk of missing an appointment so we have to pay around £50-80 for specialist private hire vehicles instead.”

Taxi drivers are often unaware of the needs of older people with health or mobility issues, and our survey highlighted a number of cases where drivers had dropped patients off a long way from the department where they had their appointment:

### ● SUPPORTER SURVEY RESPONSE

HIGH TAXI COSTS FOR REGULAR APPOINTMENTS

**In our survey among 65+’s over a quarter of respondents (26%) said they or a loved one would not be able to get to their hospital appointment at all if family and friends were unable to drive them.**



“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 the 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.”

## Where do we go from here?

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. It simply doesn't make sense to carry on with the current system as it is.

There has already been some productive thinking about how transport could be improved to better support the health system, but it is at a relatively early stage.

The Transport Select Committee has made a series of recommendations to improve transport services to isolated communities<sup>28</sup>. One of the main ideas taken up by the Government was the concept of 'total transport'. This approach involves looking at how existing transport resources can be deployed more efficiently - including hospital and school transport. At times when vehicles are not in use they could be used to fill gaps in local provision by taking a more coordinated logistical approach.

The Department of Transport is currently supporting 37 'total transport' pilots<sup>29</sup> to explore the practicalities of the idea. Devon County Council is one of the authorities taking part in the pilot to improve non-emergency patient transport services in partnership with the local Clinical Commissioning Group<sup>30</sup>. As well as making better use of local resources there is a central information service for both those who qualify for patient transport and those who do not - who are directed to community transport options<sup>31</sup>. While supporting the overall approach of total transport, the Select Committee also emphasised that it was not a substitute for properly resourced local bus services.<sup>32</sup>

The Community Transport Association are currently working with Arriva Transport Solutions to look at how cooperation between commercial and voluntary organisations can help to improve the delivery of hospital transport. They are hoping their collaboration will highlight new ways of planning, commissioning and developing services.

One of the benefits of the Bus Service Act 2017 is the requirement on bus companies to provide 'open data'. At the moment it can be difficult to follow and compare the operation of different services and timetables. Bringing this data together could make it easier to get an overview of provision and ensure better planning and scheduling to take older people to hospital.

Improvements in the reliability of bus timetables would reduce the number of missed appointments and the associated cost implications. However, the additional transport planning powers to allow the franchising of services and 'enhanced partnerships' are currently restricted to authorities with elected mayors. Ideally, Age UK would like to see power extended to other suitable local authorities.

## Conclusion

There are far too many older people who find it difficult – and often physically painful – to get to hospital appointments. There are a number of practical steps that could be taken to reduce this problem across different forms of transport. Transport must be regarded as a key component of an integrated health and social care system.

If vulnerable older people cannot actually get to the services they need then the system will fail, placing further costs on the NHS. Reasonable and cost effective measures, such as improvements to accessible design and comfort, could make a significant difference to many older people. Nationally consistent service standards could address the current postcode lottery of help and support with travel to hospital.

**In our view there are a number of broad changes which could improve non-emergency transport to hospital.**

### **IMPROVEMENTS TO PATIENT TRANSPORT SERVICES**

- A more consistent and generous approach to patient transport services so that the reach and quality of these service does not differ depending on where you live. This should include a Government review of the operation of patient transport services to promote consistency and quality, while ensuring that older people experiencing pain or discomfort are not being unfairly excluded. It should cover provision for both older people who do and do not qualify for patient transport services but need to get to a medical appointment.



## SUPPORT FOR COMMUNITY TRANSPORT

- Ensuring that hospital trusts, CCGs and local authorities have an **obligation to actively engage with community transport services.** This would help to guarantee that all older people who are unable to use public transport can get to hospital appointments.
- Greater support to **volunteer driver schemes**, particularly in more disadvantaged areas, invest in new technology to make it easier for older people or their carers to link into non-commercial and safe volunteer driver schemes.

## BETTER INFORMATION, ADVICE AND ASSISTANCE

- Clearer obligations on hospitals and GPs to offer **information about alternative forms of transport** where an older person does not qualify for patient transport. Any referral to specialist treatment away from a local area should automatically trigger advice on transport options and how to cover the costs. This should be accompanied by clear agreements between hospital trusts over patient transport services and between different local authority areas.
- All local authorities should consider a well-publicised **central information** point giving details of all local transport options (including community transport) for getting to medical appointments.
- Medical facilities having to **automatically consider the patient's transport needs**, to ensure they can get to appointment and receive assistance if required. They should review all the options if an older person does not qualify for patient transport.
- **Companion travel concessions regardless of where you live.** Local authorities should encourage volunteer companions to help older people who have worries about using public transport to get to hospital. A more flexible system would encourage more older people to use public transport and would save resources over the longer term.

29. <https://www.gov.uk/government/news/76-million-for-local-transport-in-rural-and-isolated-areas>

30. [http://www.urbantransportgroup.org/system/files/general-docs/UTG%20CTA%20Total%20Transport%20Report%20FINAL\\_0.pdf](http://www.urbantransportgroup.org/system/files/general-docs/UTG%20CTA%20Total%20Transport%20Report%20FINAL_0.pdf)

31. <https://www.newdevonccg.nhs.uk/patient-transport-information/non-emergency-patient-transport-services-for-devon-100821>

32. <https://ctablog.org/2017/06/08/new-project-launch-cta-and-arriva-transport-solutions-innovations-in-health-transport/>



## TACKLING COSTS

- Some older people are already able to use their bus passes for community transport, depending on local arrangements. Age UK believes all older people should be permitted to use their **bus pass on community transport services** to get to hospital in places **without a regular and suitable bus service**. Community transport operators should receive the same subsidies as commercial operators where they are filling a service gap. There should be a review of the subsidy system to allow more innovative and cost effective solutions that allow older people get to hospital appointments.

## ACCESSIBLE TRANSPORT

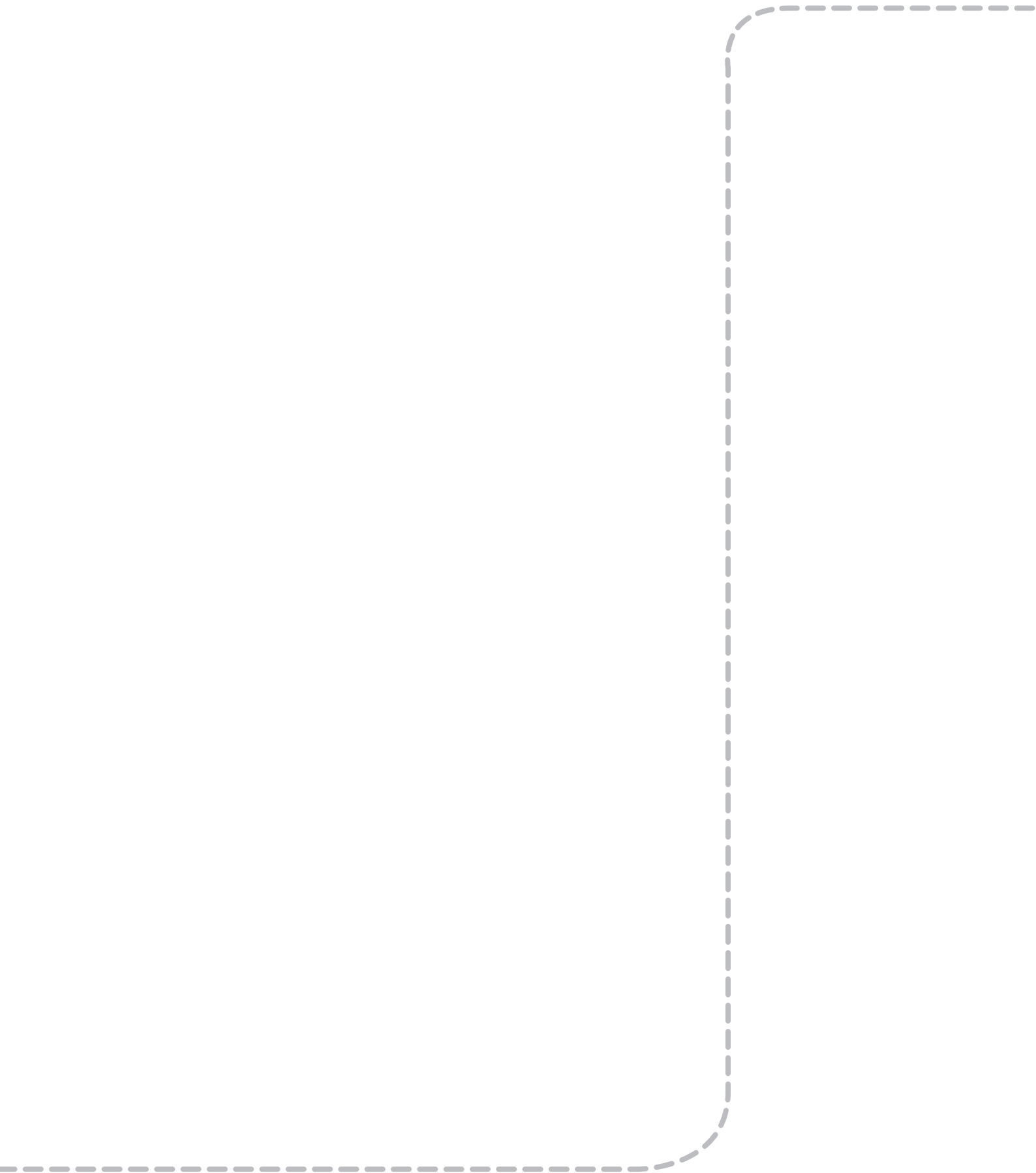
- All local authorities should have a **transport access strategy** and targets to encourage and facilitate more older and disabled people to use public transport to attend medical appointments. This strategy could be linked to pre-existing initiatives such as 'Catch a Bus' week.
- **An obligation on all bus companies** to pay for a taxi to take a wheelchair user to their stop if they are unable to accommodate them for whatever reason. This is especially important for disabled people attending hospital appointments.
- Local authorities ensuring that **regulations on accessible transport** are properly **implemented and monitored** based on the experience and feedback of service users – especially on those routes that take older and disabled people to hospital.
- All bus operators need to monitor and **implement accessibility and comfort standards for older and disabled people**. They should look at ways of making buses more accessible, comfortable and welcoming to encourage more older people to use them to get to appointments.



## PLANNING SERVICES

- Sustainability and Transformation Plans (STP) designed to integrate health and social care should automatically **consider the role of transport planning** in helping older people to get the support they need to remain independent.
- Hospitals ensuring (where possible) that **appointment times are scheduled** with community transport providers to allow more older people to get to hospital for similar treatment.
- Offering appointments to older drivers that take into consideration the time and distance involved.
- When an older driver or their family has concerns about their ability to drive to hospital, the process for referring them to a **driver mobility centre** should be made easier. They can then receive an assessment or assistance to drive safely.
- The Government doing more to require **better coordination** and collaboration between bus companies and train operators to deliver a connected, comfortable and convenient journey to hospital.
- The **planning and design of buses, bus routes, stops, information points, and public toilets** need to be geared towards older people getting to hospital and other essential services. Older people should be given more influence over how transport to hospital works to tackle any difficulties they experience.

We look forward to working with both national and local Government to further develop these ideas to ensure every older person can get to their hospital appointment safely and straightforwardly, without being made to endure anxiety, exhaustion or distress.





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