

Maintaining mobility

Understanding the unmet need for short-term mobility aids

Scotland advocacy summary

Research conducted by



"He was a prisoner. It was upsetting – he couldn't get to work, or stay as active as we usually are. With a [wheel]chair, he could have got to his job, done paperwork, been focussed and productive.

Not destructive."

Wendy, wife of Jeremy, amputee

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Introduction

"[We believe] everyone who needs a wheelchair should be able to get one quickly and easily, that is right for them and for as long as they need it."

British Red Cross humanitarian vision

The British Red Cross first started providing the short-term loan of wheelchairs during World War One. We are the largest national provider of short-term wheelchairs in the UK. We provide wheelchairs to people with a short-term mobility need (defined as a need which is six months or less), including those who have had a fall or accident, are recovering from an operation, or have an ongoing condition, such as arthritis which can affect their mobility. Last year we supplied 87,500 mobility aids across the UK, including 58,000 wheelchairs (5,600 in Scotland). However, despite loaning tens of thousands of wheelchairs each year, we are concerned that too many people requiring a wheelchair are currently unable to access one.

We believe that everybody who needs a wheelchair should be entitled to access one, for as long as they need to. For this to be delivered, both legislative and practical changes are required. The British Red Cross is calling on both the UK Government and the devolved administrations to introduce a statutory duty for the provision of short-term wheelchairs, in the same way as long-term provision. The health and social care sector must also improve the understanding and awareness of short-term wheelchair provision and the benefit this delivers to individuals, families, carers and the broader health and social care system - reducing pressures, speeding recovery time, enabling people to return home from hospital sooner and supporting them to live independently at home.

Across our work relating to health and social care, we see the negative impact of not being able to access a wheelchair when needed. People may become socially isolated, find they are unable to get to important medical appointments or work, or suffer from the well-founded fear of falling. We also see the positive impacts when people are able to access the right wheelchair at the right time.

"He was a prisoner. It was upsetting [for him] – he couldn't get to work, or stay as active as we usually are. With a [wheel]chair, he could have got to his job, done paperwork, been focussed and productive. Not destructive."

Wendy, wife of Jeremy, amputee

New British Red Cross research, detailed in this report, shows that short-term wheelchair provision is inconsistent and differs from place to place, often leaving people who would benefit from accessing a short-term wheelchair, without one.

Our research provides insight into the scale of unmet need across the UK. While we were aware of significant challenges in accessing short-term wheelchairs, the level of unmet need and the impact on people was greater than expected.

Older people and those with long-term health conditions make up a large proportion of those with mobility needs. We are therefore concerned that, as the UK population ages and the number of people with long-term and complex conditions grow, the levels of unmet need will also continue to increase.

Based on this insight and our extensive operational experience providing short-term wheelchairs to people in need, this report makes recommendations for simple improvements and practical changes to ensure that everybody who needs a wheelchair can access one that is right for them, for as long as they need it.

Key findings and recommendations

"While we knew his situation was temporary, it didn't have to be as difficult as it was. A wheelchair would have been invaluable. If we'd had a wheelchair in the run-up to and after the surgery we could have seen friends for coffee, drive to a park... It would have made our quality of life more pleasant."

Sarah, wife of Cole, recovering from hip surgery

Key findings

Inconsistent provision of short-term wheelchairs

- Less than a quarter of NHS wheelchair providers currently loan short-term wheelchairs. This means that many people who could benefit from the loan of a wheelchair are not able to access one.
- Out of 139 listed NHS wheelchair providers only 25 confirmed that they provide short-term wheelchairs. Many of the NHS providers stated that the reason they did not provide short-term wheelchairs was that they had no statutory duty to do so.

Lack of access to a mobility aid can have significant impact on a person's quality of life and their ability to recover from crisis

 65 per cent of those with an unmet mobility need experienced significant negative impact on their quality of life. This included stopping work, becoming dependent on family and friends, and becoming socially isolated and housebound.

Short-term wheelchairs can help people with mobility issues manage day-to-day life and help them to recover more quickly

- Of those who borrowed a short-term wheelchair,
 90 per cent said it was very helpful and enabled them to manage day-to-day activities.
- 87 per cent said it had made it easier for family and friends to help them.
- Almost half (49 per cent) said their wheelchair hastened their recovery time.

Lack of awareness and understanding of the benefits of using a short-term wheelchair

- Both healthcare professionals and individuals themselves have low awareness of the potential benefits of using a wheelchair when experiencing a temporary mobility restriction.
- Only 50 per cent of people who experienced a mobility issue and did not have a mobility aid thought it could have been useful.
- 42 per cent of people said that they did not want to use a wheelchair. Interestingly, participants in our case studies mentioned the perception that wheelchair use is a sign of ageing or weakness.

An estimated 4.3 million people could benefit from access to a mobility aid, such as a wheelchair

- Eight percent of those surveyed could have directly benefited from access to a mobility aid.
- Extrapolating from this figure, we estimate that 4.3 million people across the UK, had a mobility need which could have been met by a mobility aid, such as a short-term wheelchair.

44 per cent of people with a mobility need, who had not accessed a short-term wheelchair loan, thought that they would have benefitted from one

 Of the respondents who had experienced a short-term mobility need but had not accessed a wheelchair, 44 per cent thought that they would have benefitted from a wheelchair loan
 allowing them to attend appointments and to get out and about.

Key recommendations

Nationally

 The Scottish Government should introduce a statutory duty to provide short-term wheelchairs in line with long-term wheelchair provision.

Locally

 Health and care services should introduce holistic mobility assessments for people with short-term mobility needs.

- Information and training should be provided to health and care professionals to ensure that they are equipped to identify and advise people with short-term mobility needs on appropriate mobility aids, including wheelchairs.
- Statutory health and social care services should improve the provision of short-term wheelchairs in their area, by exploring ways to deliver shortterm wheelchair loans in a more consistent and joined up manner to the people who need them.



The current state of mobility aid provision

There are five NHS wheelchair services currently operating in Scotland. These services primarily provide mobility aids services to people with a permanent restriction in mobility.

There is currently no specific duty on these services, under the National Health Services (Scotland) Act 1978 ("the 1978 Act"), to provide short-term wheelchairs. At present, of the five NHS wheelchair centres, only one meets short-term need, while two others consider providing wheelchairs in clinical or end of life cases, but generally do not offer short-term provision.

There is also no statutory obligation upon local authorities under the Social Work (Scotland) Act 1968 to provide short-term wheelchairs. This creates a gap in provision, which ultimately leaves people unsure about whether they can get a wheelchair and where they could access one from.

Over the past decade, the Scottish Government has invested in wheelchair provision. However, this investment has focussed on long-term need and has not addressed short-term needs.

The current transformation of health and social care presents a clear opportunity for reform. Policy agendas such as the 2020 Vision, National Clinical Strategy and the Health and Social Care Delivery Plan focus on ensuring that people are able to live as independently as possible, accessing the right care, at the right time, as close to home as possible.

The Red Cross believes that the provision of short-term wheelchairs plays a role in delivering this agenda. As the largest national provider of short-term wheelchairs in the UK, we know that despite loaning around 58,000 wheelchairs each year, including 5,600 in Scotland, we are unable to meet everybody's needs. Too many people requiring a wheelchair are currently unable to access one. Solutions are required to meet the needs of up to 8 per cent of the population.

Our research

In recent years, the British Red Cross has worked to explore the problems and solutions associated with the provision of short-term wheelchair loans. In 2015, the Red Cross published a report in Scotland outlining the argument for the introduction for a statutory duty¹. In addition to this, we undertook UK-wide research to find out about the experience of people who had borrowed a wheelchair from the Red Cross.

This research included an economic impact assessment based on the data provided. It found that overall health and social care savings ranged from £469 to £4,607, with an average saving of £1,676 to the health system in the cases presented².

Despite this research there was, at that time, limited knowledge on the overall number of people who may benefit from a short-term loan of a wheelchair across the UK. Detailed information about the specific needs of people who had experienced a short-term mobility restriction was also lacking. Without this knowledge, it was difficult to understand the full scale of the problem and develop the appropriate responses.

As a result, the Red Cross commissioned Kantar Public to undertake new research to establish the level of need across the UK and highlight how the lack of short-term wheelchair provision is affecting people. This research included people who are unable to access a wheelchair; their carers, who may be struggling to look after them; and healthcare professionals, who may be unsure where to refer somebody.

This research comprises:

- Face-to-face surveys of 4,236 individuals aged
 16 or over from across the UK.
- In-depth interviews with eight people who have experienced a short-term unmet need for a wheelchair, as well as their wider support network. These took place in four different geographic locations.
- Interviews with healthcare practitioners in the four geographic areas covered by the case studies.

In addition the British Red Cross called 139 publicly listed statutory wheelchair providers in the UK to request information regarding their provision of short-term wheelchairs.

Harris, C. (2015). Making a Move: Increasing choice and independence for people with short-term mobility needs. British Red Cross. https://www.redcross.org.uk/about-us/what-we-do/research-publications (Accessed 6 June 2018).

² McNulty, A., Carter, C., Beswick, J. (2015). Putting the Wheels in Motion: Assessing the value of British Red Cross short-term wheelchair loan. British Red Cross. https://www.redcross.org.uk/about-us/what-we-do/research-publications (Accessed 6 June 2018).

Impact: having a wheelchair versus going without

Life with a wheelchair

The benefits of short-term use of a wheelchair were widely felt. People felt that it improved their quality of life. The majority of individuals (72 per cent) saw the value of a wheelchair in preventing further injury, while almost half (49 per cent) said that using a wheelchair hastened their recovery time.

Life without a wheelchair

For those who were not provided with a wheelchair, but experienced a mobility need relating to an injury, accident, fall, surgery or a medical condition, the majority (65 per cent) felt a significant negative impact on their quality of life.

There were several common themes and issues that appeared in their responses:

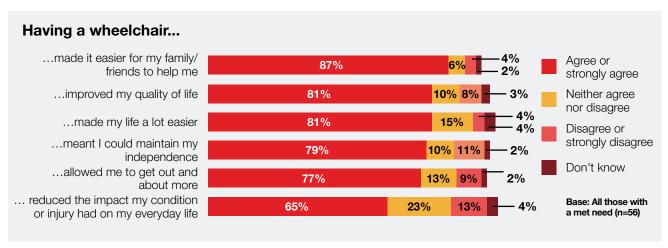


Figure 2. Respondents' experiences of short-term wheelchair use

Respondents generally agreed that having the use of a wheelchair enabled them to attend appointments and take part in social activities.

Overall, the greatest perceived benefits of a short-term wheelchair were: making it easier for friends and family to help (87 per cent agreed); improved quality of life (81 per cent agreed); and making life a lot easier (81 per cent agreed).

Isolation

"When my friends are going out walking and going to do this walk or that walk, sometimes I could cry 'cause I couldn't do it."

Sally, recovering from knee and hip replacement surgery

Without a wheelchair, people lost their independence and became increasingly isolated. Becoming housebound was a common experience. This made it difficult for people to retain a sense of wellbeing and maintain their quality of life. Their previous social connections were cut off and participants expressed how quickly they changed from being able and active to isolated, frustrated and scared to leave their home.

"Some people do get to the point that they get so socially isolated that they don't feel that they could possibly get out of the house, even to see a doctor."

District nurse

Dependency

"[My mum] was bringing me food, coming and doing shopping ... I hate it. It's like being a baby again – you can't do anything."

Tom, leg fracture from workplace accident

Both health professionals and individuals with unmet needs spoke about becoming dependent on their friends and family. While the wheelchair may not eliminate the need for support from others, it is widely acknowledged to make things easier.

Adrian's story

Adrian is in his late 70s and lives on his own. He is very sociable and a member of several clubs. Sadly, Adrian suffered a heart attack and during his recovery period he had difficulty walking. This limited his mobility for a couple of months.

Adrian spoke of the physical impact on his health that arose as a result of being confined to the house. He was told by healthcare professionals to keep moving to build up muscle strength. However, because he did not have a wheelchair, he felt limited in where he could go, and was less motivated to be active.

Adrian's daughter suggested he could move in with her temporarily so she could look after him. Adrian believed his limited mobility affected his family and friends emotionally and practically.

He was not aware that he could access a wheelchair for short-term use, and felt that his restricted mobility made him too dependent on his family and friends. He feels that had he been offered a wheelchair he would not have depended on them so much.

"I would have been able to visit the local shops without inconveniencing all the helpful friends and family I have."

Emotional wellbeing

Social isolation and dependency on others affects emotional wellbeing. In more than one case, the people we spoke to developed depression and anxiety. One person became afraid of going out at all.

"It was a very long period of being stuck in bed and feeling hopeless. When you're stuck indoors in bed all day, every day, you really will start to feel depressed. You feel like bursting into tears because you feel like your life has gone down the drain. This was going on for months and months."

Tom, leg fracture from workplace accident

Weakened physical health

"They're less likely to do anything, they're less likely to be motivated to do anything – they're frightened. They become sedentary and [then] they're at risk of developing other infections. They become at risk of developing depression."

Physiotherapist

Individuals were often advised by healthcare professionals to keep moving to build up their muscle strength and support recovery. However, without a wheelchair, people felt limited in where they could go and were less motivated to stay active as a result.

"I felt very weak. I think being [someone who enjoys walking regularly], it really hit me. You think you're invincible, but it really hits you and really strikes home."

Adrian, recovering from a heart attack

Inability to manage everyday life

"I would have been able to get around the flat and do bits and bobs, rather than crawling around on my hands and knees ... I basically lost all the skin on my knees doing it."

Mark, recovering from a fractured ankle

Participants often spoke of the difficulties and challenges they had maintaining their daily life and routines. Not being able to get around – even inside their own home, often meant they were unable to undertake normal everyday activities such as bathing, making dinner and going shopping. This led to dependency on others and the negative feelings that were often closely associated.

Affected employment

"I had no money coming in [due to an inability to work] and was surviving off credit cards and loans."

Survey respondent with an unmet need

Of those surveyed who were employed, 50 per cent said that their employment was affected in some way by their mobility issue. Of those whose employment was affected, 40 per cent found their responsibilities at work were reduced. 34 per cent had to leave employment altogether.

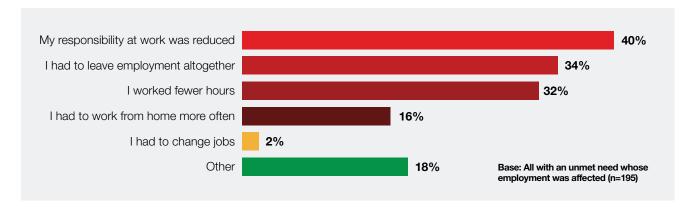


Figure 6. How unmet need affected employment (for those whose employment was affected)

Impact on family/carers

"We went from being an active, young-minded couple to a world-narrowed [one]. It was very depressing for us both. I had to make a lot of adjustments in a normally busy life. He couldn't drive me, couldn't carry the shopping. I did everything I could to make life as pleasant as possible; made meals, put on films, chatted away ... it was hard."

Sarah, wife of Cole, recovering from hip surgery

In addition to its impact on individuals, lack of mobility affects the lives of family and friends. Some had to add the role of carer to their normal day-to-day tasks. Others had their lives disrupted. For example, having the affected individual move in with them or having to defer their studies.

"I had to do everything. I literally had to do everything. In the beginning, I had to wash him, I had to prepare all the food, I had to dress him ... a wheelchair wouldn't have solved everything, but it would have enabled him to get around without me driving."

Suzy, partner of Mark, recovering from fractured ankle

Impact on the health and social care system

"It would impact most on primary care services. If [patients] are not able to get out, then we are having to visit at home ... which is much more timing consuming and much more expensive for the NHS."

GP

Not being able to access a wheelchair can also lead to additional strains on the health and social care system. At its most extreme, this can lead to individuals spending longer than necessary in hospital. Healthcare professionals also spoke about people having to rely on costly home visits because they could not leave their home. People also missed appointments and in some cases, experienced deterioration in their health.

This reinforces findings contained within previous British Red Cross research³. It found that access to a wheelchair can prevent, reduce and delay the need for care and support. An economic evaluation demonstrated that overall health and social care savings from the nine case studies contained within the research ranged from £469 - £4,607, which is an average saving of £1,676.

³ McNulty, A., Carter, C., Beswick, J. (2015). Putting the Wheels in Motion: Assessing the value of British Red Cross short-term wheelchair loan. British Red Cross. https://www.redcross.org.uk/about-us/what-we-do/research-publications (Accessed 6 June 2018).

Jeremy's story

Jeremy is semi-retired and runs his family business with his sons. He enjoys DIY and walking his dogs. Sadly, Jeremy developed vascular problems in one of his legs, which meant he could barely walk or stand. As a result he had to have his leg amputated from the knee down.

Following his surgery Jeremy was unable to go home because he couldn't use his prosthetic limb or crutches. The hospital did not have a wheelchair he could use in the short-term and no wheelchairs were available locally, without going through a private provider. Jeremy had to stay the night in hospital and was only able to get home once his son found a private wheelchair company.

"I had to hire from a private company. [I] would have rather given that money to a charity to support the work they do. Not to mention, I stayed a night in hospital for no reason."

Jeremy is now able to use his prosthetic leg, however he still has regular periods of limited mobility when he injures his stump and cannot use his prosthetic leg. These range from one week to several months, depending on the severity of the injury.



Barriers to access

This research also explored the barriers that exist to people accessing short-term wheelchairs. It found that too often people who could benefit from a wheelchair don't get one. This is for a number of different reasons, some of which are outlined below.

Lack of awareness

There is a lack of awareness of local provision and eligibility among both health and care professionals and people with mobility needs. Many participants noted that they just weren't aware that a short-term wheelchair could be of benefit, and if they were they did not know where to get one from.

Sally's story

Sally is in her early 70s. Prior to the issues that caused her restricted mobility, Sally had an active social life and was interested in health and fitness. Unfortunately, as a result of an old sporting injury Sally required two knee replacement operations and later a hip replacement.

Sally had difficulty walking and standing after her operations. She needed a chair in every room in the house, including the shower.

Sally really struggled to access a short-term wheelchair, which she feels would have prevented her from becoming isolated and anxious about leaving her home.

She feels that there needs to be better awareness of local provision on wheelchairs, and that this needs to come from health care professionals.

'Someone should have said: "Do you want a wheelchair for your first six weeks? ... There was no information about where you could get one from. Nobody knew anything about them."

Expectation that a wheelchair would be offered if needed

Participants in the case studies did state that they relied on health professionals to inform them of what they needed to best support their needs and assist their recovery. However, the research suggests that health professionals did not proactively recommend a short-term wheelchair. This may be due to the fact that currently, they cannot provide them.

That aside, people did feel it was the role of health professionals to give advice and explain the options for mobility aids. They felt that they were best placed to understand people's mobility needs and advise them on how to access that support.

"You trust the professionals will give you the help you need. So if they think you will benefit from a wheelchair, you think they'd give you one."

Leanne, experienced neurological tremors

Perceived stigma of using a wheelchair

"People in wheelchairs to me: is that the end of their life? I didn't want to be seen like that."

Adrian, recovering from a heart attack

The findings show that there is still significant perceived stigma associated with using a wheelchair. For some participants, wheelchairs prompted images of frailty, ill-health and ageing.

Our research shows that although 44 per cent of respondents with an unmet need thought that they could have benefited from having access to a wheelchair, only 17 per cent had considered using a wheelchair at the time. Certain groups were more likely than others to consider using a wheelchair, with 21 per cent of women considering using a wheelchair, compared with 12 per cent of men.

Of those who reported their health was bad or very bad, 28 per cent would have considered using a wheelchair, compared with 8 per cent of those who reported their health was good or very good.

"There is a bit of a stigma with wheelchair users, so they actually don't want to be in a wheelchair, especially someone who is quite young."

District nurse

Practicalities of access to a wheelchair

"The problem with short-term wheelchairs is it can take a long time to get one because of limited availability, and by the time a person gets one they might not need it anymore."

District nurse

Practical difficulties including long waiting periods, restrictive criteria, limited availability, challenges of collecting and returning a hired wheelchair were all mentioned as barriers to individuals accessing a short-term wheelchair.

"It is not easy to get patients short-term use of wheelchairs ... everything takes so long for assessments."

Home visit nurse

Cost of wheelchairs

While in the survey cost did not come out as a barrier to accessing a short-term wheelchair, both case study participants and healthcare professionals cited the cost as being prohibitive.

Respondents to the survey who did not use a wheelchair for reasons other than they didn't think it would be beneficial, were asked if they would have been either happy to pay for, or make a donation towards loaning or buying a wheelchair. Almost half (47 per cent) said they would have been happy to make a payment or donation.

However, cost was a recurring theme, particularly for those who were unable to work due to their condition.

"I looked online, the cheapest was £150. When you've been in hospital for that long, you've not been working and don't have the money."

Tom, fractured leg from a workplace accident

Recommendations: What needs to happen now

"Let's not always look at things from the health point of view. Let's allow someone to have some independence and some quality of life."

Physiotherapist

The British Red Cross believes that action needs to be taken to ensure that people who have a short-term mobility need can access a wheelchair when they need it, and for as long as they need it.

We believe that the clearest way to deliver this is through the introduction of a statutory duty to provide short-term wheelchairs in line with long-term provision.

In the meantime, we call upon the health and social care sector to work to improve the assessment process for people with mobility needs. Collectively, we need to better meet the needs identified, provide information and training on short-term wheelchair loans to health and care professionals, and increase and improve the provision of short-term wheelchairs at a local level.





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