

# Financial impacts of living with multiple long-term conditions – plain English summary

## 1. What is this about?

The number of people who have a Multiple Long-Term Condition (MLTC) has increased fast, especially for older adults. People who live in poorer areas are 19% more likely to experience MLTCs and 15 years earlier when compared to people living in better off areas<sup>1</sup>. We are currently doing some research to better understand the impact of living with MLTCs, life points when the conditions happen, and how different conditions experienced together can worsen impact. One area of impact for people living with MLTCs is **financial**. Anonymised quotes depicting lived experience have been provided by members of the Patient and Public Involvement (PPI) advisory group with their permission to be used in this report.

## 2. Summary of this Document

The focus of this report is about existing policies created by current and past UK governments to help people manage the **financial impact** of living with multiple long-term conditions. There are 3 themes which will be explored:

- i. Income deprivation (This means people who are on a low income and living in poverty)
- ii. Medication costs
- iii. Appointment costs

One of the common issues that have come up in each of these themes is the fact the support offered is not designed in mind for those with MLTCs. It means any help that is given is only by chance, rather than being directly targeted for people in this group. There are problems around barriers to applying for benefits, the large amount of effort

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<sup>1</sup>[Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study - The Lancet](#)

needed to meet its requirements and the poor quality of the support that is available. People who need it most find it hardest to apply.

*People living with MLTCs told us “There is very little help and guidance offered, the emotional work is immense, and people are left struggling to afford the basic necessities.”*

### 3. About the language we use

The ***Multidisciplinary Ecosystem to study Lifecourse Determinants and Prevention of Early-onset Burdensome Multimorbidity (MELD-B)*** study previously used the word ‘burden’ to describe the negative impact people face when living with multiple conditions. After listening to the views of its Patient and Public Involvement (PPI) advisory group, the study team now describe this aspect as ‘**impact**’ and ‘**work**’ instead.

We will also use the description of ‘**living with multiple long-term conditions**’ rather than ‘living with multimorbidity’.

### 4. Income deprivation

People living with MLTCs often experience a change in their social circumstances, including the amount of money they can earn or receive in benefits. There are a range of Government benefits that people living with MLTCs can access. However, even if someone is eligible for several of these, the overall income is about 65% less compared with someone working and earning an average weekly wage. Successfully applying for benefits also requires significant effort and time-consuming paperwork.

We have made some recommendations to Government about the way they support people living with MLTCs. This includes making the application process for benefits easier and to involve people living with MLTCs in planning any changes to the benefit systems or in the way the healthcare system work, so it is better for people who use them.

*People living with MLTCs told us: “The benefits system creates a huge strain with the energy and abilities required to apply, it’s inflexible with fluctuating conditions,*

*and adds to psychological and mental health problems many people with MLTC's already have".*

## 5. Medication Costs

People with MLTCs usually take several different medications. Prescriptions are expensive and some people have missed out on taking important medication because they have not been able to afford the prescription costs.

In England there are several criteria for receiving free prescriptions including if someone has one of a limited number of medical conditions. Some people living with MLTCs will not be exempt from paying for prescriptions and for many paying for a **pre-payment certificate** can cap the expense. This is still a large expense for people on low incomes who may not be able to work due to their MLTCs or have had to change jobs or work less hours.

People living with MLTCs told us: *"I have long term conditions which require management with medication. I am not eligible for free prescriptions even though I will have to take medication for the rest of my life and one of my conditions could be potentially life threatening. If I do not take my medication, I will end up using health services more and costing more. Yet my medical conditions are not on the list for free prescriptions. It is not clear how the list is decided...I have a PPC which although cheaper it is still extra money to find on top of other living costs."*

## 6. Going to Appointments

People living with MLTCs will often need to attend multiple healthcare appointments which create an additional expense due to travel or parking costs, missing work or having to pay for childcare. There is a **Healthcare Travel Costs Scheme** which offers some support to some people meeting certain criteria but requires lots of paperwork.

**Patient transport services** can also help people get to appointments but can result in long journey times or delayed appointments for those using the service. Some MLTCs require appointments that are far from

where people live and there are no schemes which can compensate people that might need to book overnight accommodation.

People living with MLTCs told us: *“Travel to appointments means a car journey to the GP or hospital because of where I live. There is no viable public transport option. On top of that appointments for me and my family have been all over Hampshire...The current system is set up for the convenience of clinicians (having regional centres or sending you to alternative sites because of demand) but places more demands on patients in terms of travelling time and cost.”*

## 7. What action should be taken from these findings?

There are several ways that the government and policy makers should seek to change and reduce some of the burden that people with MLTCs face with these challenges:

- a. The **NHS Integrated Care Boards** across England should work towards making MLTCs/multimorbidity a priority as part of their strategic plans for healthcare in local communities.
- b. Applying for specific benefits, like **Personal Independence Payment (PIP)**, are only available online and create a difficult barrier for people who might need this type of support. Providing accessible alternatives that reduces this problem should be considered.
- c. The level of stress and intensity when applying for financial assistance often leads to unfair rejections, which then need to be appealed at tribunals. By working alongside people that have lived experience to design services and build understanding of how the application process can be made easier for benefit applicants, these processes can improve.
- d. Free parking in NHS car parks should be extended in cases where people with MLTCs are attending regular appointments.

If you are someone living with one or more long term conditions, you may find it helpful to **check whether you are eligible for:**

- **free prescriptions**
- **assistance with travel to appointments**
- **state benefits**

The following links may be helpful:

- [Check if you can get free prescriptions - NHS \(www.nhs.uk\)](#)
- [Save money with a prescription prepayment certificate \(PPC\) - NHS \(www.nhs.uk\)](#)
- [Healthcare Travel Costs Scheme \(HTCS\) - NHS \(www.nhs.uk\)](#)
- [How to organise transport to and from hospital - NHS \(www.nhs.uk\)](#)
- [Benefits - Citizens Advice](#)
- [Personal Independence Payment - Citizens Advice](#)
- [Tackling Financial Insecurity Together | Turn2us](#)
- [Carer's Allowance | Carers UK](#)

## Glossary of terms

|                             |                                                                                                                                                                                                                                                                      |
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| Carers Allowance            | A financial benefit for individuals who care for someone who has an illness or disability at least 35-hours a week. This is a benefit assessed on existing education and employment status. This benefit stops at state retirement age.                              |
| Disability Living Allowance | (England, Wales and NI only) A financial benefit that is paid to support disabled children under the age of 16 who have a diagnosed health condition. Some adults may still receive the former DLA before the introduction of Personal Independence Payment in 2013. |

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| Healthcare Travel Costs Scheme                                                                                                | An NHS scheme that allows eligible people to claim back travel expenses when referred to hospital or other NHS premises for specialist NHS treatment or diagnostic tests                                                             |
| Integrated Care Board                                                                                                         | The part of the health system responsible for planning services for the local population; they form part of the integrated health systems which includes other organisations like local authorities and the voluntary sector.        |
| Multidisciplinary Ecosystem to study Lifecourse Determinants and Prevention of Early-onset Burdensome Multimorbidity (MELD-B) | The name of the research project being conducted at the University of Southampton to try and identify time points in peoples' lives when MLTCs could be prevented                                                                    |
| Multimorbidity                                                                                                                | Means living with multiple long-term conditions                                                                                                                                                                                      |
| Multiple Long-Term Conditions (MLTCs)                                                                                         | A term describing people who live with two or more health conditions that cannot be cured and that often require ongoing monitoring or treatment                                                                                     |
| Patient Transport Service                                                                                                     | An NHS service to help some eligible people travel to hospital but can vary depending on where you live                                                                                                                              |
| Pension Credit                                                                                                                | A financial benefit for people who at retirement age (currently 66) may receive additional funding to increase their pension based on criteria of low income and other circumstances (e.g carer).                                    |
| Personal Independence Payment                                                                                                 | (England, Wales and NI only) A financial benefit, similar to DLA for children, which supports disabled adults (over 16) and those with long-term conditions to support the extra costs which they might face. It is not based on the |

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|                        | individual's employment or education status.                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| Prepayment Certificate | An NHS certificate paid for in advance that lasts for a defined period of time and that offers savings over paying for individual prescription costs                                                                                                                                                                                                                                                                                                                                                 |
| Statutory Sick Pay     | A minimal rate of income which is paid to a person in employment that is sick from work for 3 days or more. It can be paid for up to 28-weeks until the point an employee returns to work.                                                                                                                                                                                                                                                                                                           |
| Universal Credit       | <p>Universal Credit is a combined benefit for working-age people, who may or may not be employed, which replaced 6 previous benefits. These are:</p> <ul style="list-style-type: none"> <li>• Income Support</li> <li>• Income-based Jobseeker's Allowance (JSA)</li> <li>• Income-related Employment and Support Allowance (ESA)</li> <li>• Housing Benefit (England, Scotland and Wales) / Housing Benefit (Northern Ireland)</li> <li>• Child Tax Credit</li> <li>• Working Tax Credit</li> </ul> |