motor neurone disease association

Policy in Practice

The implications of Universal Credit for people living with motor neurone disease (MND)

Universal Credit

Contents

Executive summary

The Motor Neurone Disease Association (MND Association) is interested in the impact that Universal Credit will have on people living with motor neurone disease (MND).

Policy in Practice has been commissioned to carry out this research and present the findings in a report. The report provides a background to Universal Credit and looks in-depth at those elements of Universal Credit that bear most relevance to people living with MND.

Claim management

The report examines the Universal Credit claim process, highlights how this differs from legacy benefits, and the resulting impacts on those living with MND.

The move to a single out-of-work benefit simplifies the move to benefit support for those that can no longer work, and the online nature of Universal Credit application and claim management may, for some of those living with MND, be more accessible. However, the report finds that for those living with MND who do not meet The Department for Work and Pensions (DWP) definition of terminal illness, the claim process can be stressful and the Universal Credit requirement for interview by generic work coaches is inappropriate. Where a claimant certifies as terminally ill, the process is generally smoother as the special rules for the terminally ill enable greater assistance with the claim process and by-pass the requirement for the claimant commitment interview and Work Capability Assessment (WCA).

In some instances, processes and guidance to assist claim management are nominally available but rarely used. This includes the use of Appointees to manage claims, visits to assist with verification and interview, and more appropriate and sensitive claimant interviews. Universal Credit is a new benefit and it may be that some of these processes are not yet fully embedded.

For those with MND the introduction of the requirement for explicit consent before the DWP can discuss a claim with a representative creates additional barriers to claim management. The need for explicit consent prevents those assisting claimants living with MND, such as officers of the MND Association, supporting claimants through the claim process. This may be particularly problematic where claimants do not wish to face the prognosis required for certification of terminal illness.

The report makes recommendations that would assist the customer journey for those with MND.

The recommendations are that:

- **DWP staff guidance should include recognition of the exceptional nature of progressive terminal conditions, even when the claimant does not state the terminal nature of the condition or the prognosis. This would trigger additional support and awareness of the option of nominating an Appointee.**
- **Progressive terminal conditions should be treated as an exceptional circumstance under Regulation 16 of the Universal Credit Regulations 2013. Thereby averting the requirement to attend a claimant commitment interview.**
- **Home visits should be offered by the DWP as a matter of course to all those with progressive terminal conditions.**
- **Third parties should be able to notify the DWP of a claimant's condition and therefore trigger the special rules for those with terminal illness. Implicit consent should be accepted for specific notifying people or agencies.**
- **Claimants living with diseases that have a rapidly progressive nature should be treated in the same manner as those that have a certified prognosis of death within six months. The claimant should be automatically assigned to the Limited Capability for Work and Work-Related Activity (LCWRA) group and receive additional support.**
- **The DWP should change the definition of terminally ill to enable it to encompass progressive terminal diseases. In particular, the "reasonable expectation of death in six months" clause should be omitted from both the DWP definition of terminal illness and the requirement for issue of the DS 1500. Defining terminal illness should be left to medical professionals.**

Benefit support

A change in the benefit system will always have winners and losers. The amount that a household will gain or lose will depend on the individual circumstances of the household and this has been highlighted in the case studies at the end of this report.

In general, those living with MND are most likely to fall within the most supported group for Universal Credit and receive the LCWRA additional support element within their benefit. Most claimants will therefore retain similar levels of support as under legacy benefits. However, some people living with MND will lose support:

- Those in receipt of disability benefits but not in the most supported group of Universal Credit could lose substantial amounts of support due to the removal of disability premiums.
- Those with savings over £16,000 who receive Child Tax Credits under legacy benefits will no longer receive any support under Universal Credit. For some, this loss of support will be hundreds of pounds a month.
- Changes in the treatment of income protection insurance under Universal Credit will reduce the level of award, especially if the payment is as a lump sum.

- The conversion of mortgage interest payments to a loan will mean that many households will no longer receive support with mortgage payments. This is a change that affects legacy benefits as well as Universal Credit.

Specific recommendations made in this report are that:

- The capital cut-off limits will mean reduced support for those moving from tax credits to Universal Credit who have capital over £16,000. This could particularly affect those who receive lump-sum insurance payments. It would assist those with MND if some of these awards could be disregarded for Universal Credit assessment purposes, or a grace period introduced.
- Individual income protection regular payments should be treated as earned income under Universal Credit, as under legacy benefits.
- The time limit before a claimant can apply for mortgage interest support loans should be reduced from the current nine months for those with progressive terminal illness.

The report contains illustrative case studies that link to the Policy in Practice benefit and budgeting calculator, this enables further modelling of benefit awards for those with MND.

Foreword by Tracy Smith

Michael and I married in 2013. He was diagnosed with MND aged 33 and passed away in January 2018. In the last year of his life I became his primary carer. Policy in Practice and the MND Association asked me to share my experience of the support available through the benefit system.

There has to be a separate process for people with MND, as if they do not have partners they have no help with forms. Given the fast progressing nature of MND, it can be too fast before they have a chance to deal with it.

Applying for benefits is very hard. There should be one form to fill out that covers everything as opposed to a form for every single thing you want to claim.

There needs to be an easier way for people in our situation to find out what we are eligible for. I had no idea about some stuff and found out that I was actually able to make a claim when it was too late or even months after Michael passed away.

The new rule on bereavement benefit came in six months before Michael passed away and in my own case this now means I'll have to go back to work when my daughter Sienna is three and a half. I worked full time, from age 16. I only stopped working to look after Michael. My husband and I both paid into the system. I feel that the system has not kept its side of the bargain.

Everything is very difficult for a person who has just been given a terminal diagnosis!

I would suggest the following improvements:

1. A fast track method for everything: benefits, medication, equipment, care etc.
2. One form to assess all benefits.
3. Access to information of support available through benefits, and charities that are able to help financially.

Foreword by Deven Ghelani

Policy in Practice was founded to make the welfare system simple for people to understand, and improve policy by bringing voices from the frontline into the policy development process.

It is a real privilege for Policy in Practice to have been able to work on this this report, and share Tracy's experience with policymakers, in order to improve others' experiences of the welfare and care systems.

I had the great privilege of going to school with Michael Smith, where he was known as 'Mickel' on the football pitch, and whenever he was joking around, which was most of the time.

This report is dedicated to Michael, his wife Tracy and their daughter Sienna.

Deven Ghelani
Director, Policy in Practice.

Background to project and scope

Universal Credit is a new benefit that rolls six working-age, means-tested benefits into one monthly payment. It is gradually being rolled out across the UK, with all Jobcentre Plus (JCP) offices expected to offer it to most claimants by 2019.

The Motor Neurone Disease Association (MND Association) is interested in the impact that Universal Credit will have on people living with MND. Specifically, the MND Association want to understand the claim-making process under Universal Credit, how this may affect the experience of claiming benefits for people living with MND, and how actual benefit amounts may differ under Universal Credit for people receiving disability benefits.

The MND Association hopes to use this to inform and educate members, as well as for internal reference. Additionally, the MND Association would like to use the findings and tangible examples from this report to inform its future advocacy work around Universal Credit. This would build on the MND Association's previous advocacy success, where it successfully campaigned for people living with MND to be officially exempted from work capability reassessments under Employment and Support Allowance (ESA).

Policy in Practice has been commissioned to carry out this research and present the findings in a report.

The initial phase of the research took the form of telephone interviews with MND Association advisors, who frequently support people living with MND in the benefit claims process. These interviews allowed us to better understand the journeys through the benefits system that people living with MND typically take, plus the range of obstacles that they may face in the process.

The second phase of the research involved a review of literature and legislation around Universal Credit. The findings from this will provide an overview of the political and financial motivation behind Universal Credit, plus some of the benefit's main features in terms of administration, payment, claim management and calculation of entitlements. Particular focus is placed on the elements of Universal Credit that bear most relevance to people living with MND, such as the appropriateness of work interviews, the accessibility of the claim-making process and issues around explicit consent. The findings from these two research phases make up the main body of the report.

Finally, in the final section of this report we provide four case studies. These will help to illustrate the challenges considered in section 2, and provide tangible figures on the changes in benefit support that different family types could experience under Universal Credit. Each case study will include a link to Policy in Practice's Benefit and Budgeting Calculator, where the MND Association will be able to explore and vary each case's circumstances.

The MND Association is a registered charity. Registered charity No. 294354.

Motor neurone disease – an introduction

Motor neurone disease (MND) is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves (motor neurones) that control movement so that muscles stop working. At any one time, MND affects up to 5,000 adults in the UK.

There are four main types of MND. While symptoms vary among these, over the course of their illness most people with MND will be trapped in a failing body, becoming unable to move, talk, swallow and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. A few people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia. While there is no cure for MND, symptoms can be managed to help achieve the best possible quality of life.

MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual. A person's lifetime risk of developing MND is up to one in 300. While it can affect adults of any age, MND is more likely to affect people over 50.

Because of the often rapid progression of MND, people with the illness will usually have to give up work. In many cases, the partner of a person with MND will also have to reduce their working hours or leave their job altogether in order to become a carer. Such a situation can place families where a member has MND under significant financial stress, so that they may need to rely on benefit support from the state.

Data from the MND Association's Benefit Advice Service shows that, in the eight months from April 2017 to 31st December 2017, 691 benefits enquiries were made by people with MND in England, Wales and Northern Ireland. The MND Association estimates that this corresponds to just under £1.1 million in benefits that people with and affected by MND were eligible to claim. Over half of the people making these enquiries were under the age of 65, and therefore largely eligible to receive Universal Credit.

People with MND may be eligible to receive a range of benefits, depending on their particular financial circumstances and sometimes also on the level of progression of the illness. Social Care support is often also available from local authorities, which may vary from area to area.

For people with MND that are of pension age, the benefits they may access are expected to remain largely the same in the next few years. However, for people with MND of working-age, most means-tested benefits they can access will come under the umbrella of Universal Credit. As such, this report will focus on people with MND that are of working-age.

Universal Credit – an introduction

Universal Credit is a single monthly payment for households on low to middle incomes. It is available to people both in-work or out-of-work, as long as capital is less than £16,000. Universal Credit replaces the following six current benefits:

- Housing Benefit
- Working Tax Credit
- Child Tax Credit
- Income Support
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance.

The combination of in-work and out-of-work benefits means that Universal Credit will be available to households with a wide range of incomes.

Example: A household with two children and a rent of £1,300/month in London can earn £50,000 gross/annum and still qualify for Universal Credit of £146/month.

Universal Credit is calculated each month by reference to income in the previous monthly assessment period. There are no limits on the number of hours a person can work in order to claim. Because of this, Universal Credit is able to provide continuous support as people change their earnings and move in and out of work. This is not always the case under legacy benefits, with many claimants facing a "cliff-edge" in benefits if they exceed a particular number of hours.

Because Universal Credit is assessed monthly, claimants must actively manage their Universal Credit account. This is in order to inform the DWP of changes in employment and other changes of circumstances. For employed claimants, information on earnings is sent directly to DWP from HM Revenue & Customs (HMRC), but self-employed claimants must inform the DWP of their earnings each month. To facilitate this active claim management, all claimants have an online journal with which they communicate with the DWP.

Claims are made online and assessment and administration of claims takes place at Universal Credit Service Centres which are geographically removed from JCP offices. Claimants will need to attend at least one interview (the claimant commitment interview) at their local JCP before their claim starts. If they are incapacitated for work, all further communication can be undertaken online. If the claimant is expected to work, or work longer hours, then ongoing appointments will be made with a work coach at the JCP. Claimants can also attend their local JCP for assistance with the online claim process and verification of their identity if this cannot be done online. The DWP is currently reducing the number of local JCP offices as more claim administration moves to the Service Centres.

Universal Credit is paid monthly in arrears. Payment is made directly into the claimant's bank account and should be made within five days of the end of an assessment period. Couples make joint claims and receive a joint award – they can nominate the person to whom the award is paid.

Some other means tested benefits, plus all non-means tested benefits will remain in place and be paid separately to Universal Credit. These will continue to be paid on a weekly-based frequency. The key ones are:

- Contribution-based Employment and Support Allowance. This is now called "new-style ESA"
- Contribution-based Jobseekers Allowance. This is now called "new-style JSA"
- Carer's Allowance
- Child Benefit
- Council Tax Support
- Disability Living Allowance (DLA), Personal Independence Payments (PIP) and Attendance Allowance (AA)
- Bereavement Allowance.

Although these benefits lie outside Universal Credit, the introduction of Universal Credit does have an impact on some of these and this is covered later in this review.

A comprehensive guide to Universal Credit is available here.

Calculation of Universal Credit

Universal Credit is made up of a standard allowance per household (which is dependant on household circumstances) plus additional elements for housing, being a carer, childcare, incapacity for work, and child disability. The sum of the allowance and elements is the maximum Universal Credit.

The maximum amount of Universal Credit will be awarded if the household has no other income and savings or capital of £6,000 or less. If the household has other income or savings, deductions are made from this maximum. The maximum award is reduced by:

- a amount equal to any non-earned income (eg contributory ESA)
- 63p for every £1 of net earned income
- notional income derived from savings over £6,000.

Not all income is taken into account. Some types of non-earned income are ignored (such as DLA, PIP, AA, or Child Benefit) and earned income may be subject to a work allowance – this is the amount that can be earned before maximum Universal Credit is reduced. A work allowance is applied if the claimant has children or has limited capability for work because of illness or disability. Income from a lodger is not taken into account under Universal Credit, whereas it is considered when calculating legacy benefits.

Employer-paid benefits, such as Statutory Maternity, Paternity, Adoption and Sick Pay are treated in the same way as earnings.

Unearned income that will be taken into account includes Carer's Allowance, New-style Jobseeker's Allowance (JSA), New-style Employment and Support Allowance (ESA), and income from pensions.

An example showing the steps of a Universal Credit calculation is shown in Figure 1 below:

Universal Credit

Step 1: Calculate any Housing Element

Gross monthly rent	£ 1300.00
Deduction due to ineligible services and charges	£ 0.00
Deduction due to maximum rent allowed (LHA)	£ 338.90
Housing Component	£ 961.10

Step 2: Calculate Maximum Universal Credit

This is made up of elements based on household circumstances

Adult	£ 498.89
Child	£ 508.75
Carer	£ 156.45
Housing	£ 961.10
Maximum Universal Credit	£ 2125.19

Step 3: Calculate income

This is 63% of net earned income after application of the work allowance plus non-earned income & income from savings. Private pension contributions are deducted.

Net earned income	£ 800.00
Minus work allowance	£ 192.00
Income after work allowance	£ 608.00
Earnings for assessment (63% of net earnings)	£ 383.04
Income from savings	£ 43.50
Total income	£ 426.54
Income for assessment	£ 426.54

Step 4: Deduction due to income & savings

Deduct income from maximum Universal Credit

Maximum Universal Credit	£ 2125.19
Minus income for assessment	£ 426.54
Universal Credit	£ 1698.65

Figure 1: Calculation of a Universal Credit award, in £/month

National roll-out of Universal Credit

Universal Credit is being introduced gradually throughout the UK with roll-out by JCP areas. After several delays due to issues with administration plus generalised concern around its impact on vulnerable people, it is expected that Universal Credit full-service will be available in all areas by December 2018.

Where Universal Credit has been introduced, all new claims must be for Universal Credit rather than legacy benefits. Households that are currently in receipt of other in-work and out-of-work benefits will move to Universal Credit if they have a significant change of circumstances. The exception to this is households with three or more children who will remain in receipt of legacy benefits until 1 February 2019. Changes of circumstances that would trigger a move to Universal Credit include:

- a change in employment status
- partner joining or leaving the household
- someone becoming, or no longer being, a carer
- moving from contributory ESA to income-based ESA
- failing the work capability assessment
- moving home to another local authority.

Households that move to Universal Credit due to a change of circumstances will not receive transitional protection to cover any possible reduction in benefit support.

Claimants who are in supported housing or temporary accommodation will move to Universal Credit in the same manner as other claimants, but their Universal Credit will not include any housing support, which will continue to be met by Housing Benefit. The temporary nature and additional costs of this type of housing has led to ongoing additional consultation on future funding under Universal Credit.

Any households remaining in receipt of legacy benefits in July 2019 will be moved to Universal Credit at some point between July 2019 and March 2022 under managed migration. Households moving to Universal Credit under managed migration will receive transitional protection to ensure that they do not lose any benefit support. This protection will last until they have a significant change of circumstances or make a new claim.

The implications of universal credit for those with MND: claim management

Claim management under Universal Credit brings both benefits and challenges for those living with disability.

Online claim management

Claiming Universal Credit, and management of the claim, is online. This has significant advantages for some of those with mobility problems or where progression of the disease has affected speech. Where online claim management is not possible, perhaps due to MND affecting the claimant's ability to use their hands, the claimant has the right to request application by phone, or in person at the local JCP. Where mobility issues or disease progression means these are not options, claims can be managed through an appointee. The rules around claiming Universal Credit via an appointee remain much the same as with legacy benefits. Application to be an appointee will need to be discussed initially with the DWP via the Universal Credit helpline.

Nominating an appointee

An appointee is somebody given the right to deal with the benefits of someone who cannot manage their own affairs, either because they're mentally incapable or severely disabled. An appointee can be an individual (eg, a friend or relative), or an organisation/representative of an organisation (eg, a solicitor or local council). If they apply and are accepted, the appointee would be responsible for filling out and signing any benefit claim forms, informing the relevant benefit office of any changes in circumstances of the claimant, and spending the benefit. If the claimant requiring an appointee is receiving a range of benefits, the process of becoming an appointee may need to be done individually for certain benefits. Due to the restrictions posed by MND, many people living with the disease may wish to select an appointee to manage their benefits on their behalf.

In exceptional circumstances, if someone is unable to claim online or through the telephone, the DWP may make a home visit to initiate a Universal Credit claim. In January 2017, Caroline Nokes MP, stated that:

"The DWP has a home visiting service which we can extend to all disabled claimants who ask for it when their circumstances make it difficult for them to go to a jobcentre. We want our work coaches to provide tailored support for each of their claimants, to have a relationship with them, and to understand their specific needs.[1]"

1 Hansard, 30 January 2017. Volume 620. https://hansard.parliament.uk/Commons/2017-01-30/debates/EBCFB042-6606-49B3-9E83-03FB31981159/JobcentrePlusOfficesClosure#contribution-3E5BD11F-8748-428F-991C-E4AE465DD025

Interviews with MND support workers indicated that this option is not commonly used. It may be that requests for a home visit have not been made or that these have been refused.

The claim process is somewhat convoluted. Firstly, a claimant must register with the DWP through the online claim page. This is to ascertain if they are in a Universal Credit area and that they can claim Universal Credit. If they can claim, a validation email is then sent that needs to be actioned. Once this validation has occurred, the claimant can complete the online claim form. This must be completed within 28 days of validation and necessitates the claimant gathering all relevant documentation beforehand. The claim is estimated to take approximately 40 minutes, although for people living with a disability it can take considerably longer. Support workers indicate that completion of the claim can be extremely long and arduous for some of those with progressive MND. The typical claim journey is shown below[2]:

The online claim form asks if the claimant has a terminal illness and the prognosis. In some instances, those with terminal illness prefer not to know that the illness is terminal, and others do not wish to know the prognosis. However, if these questions are not answered, the person will not be provided with additional support and information regarding the DS1500, exemption from the claimant commitment interview, and fast-tracking of claims.

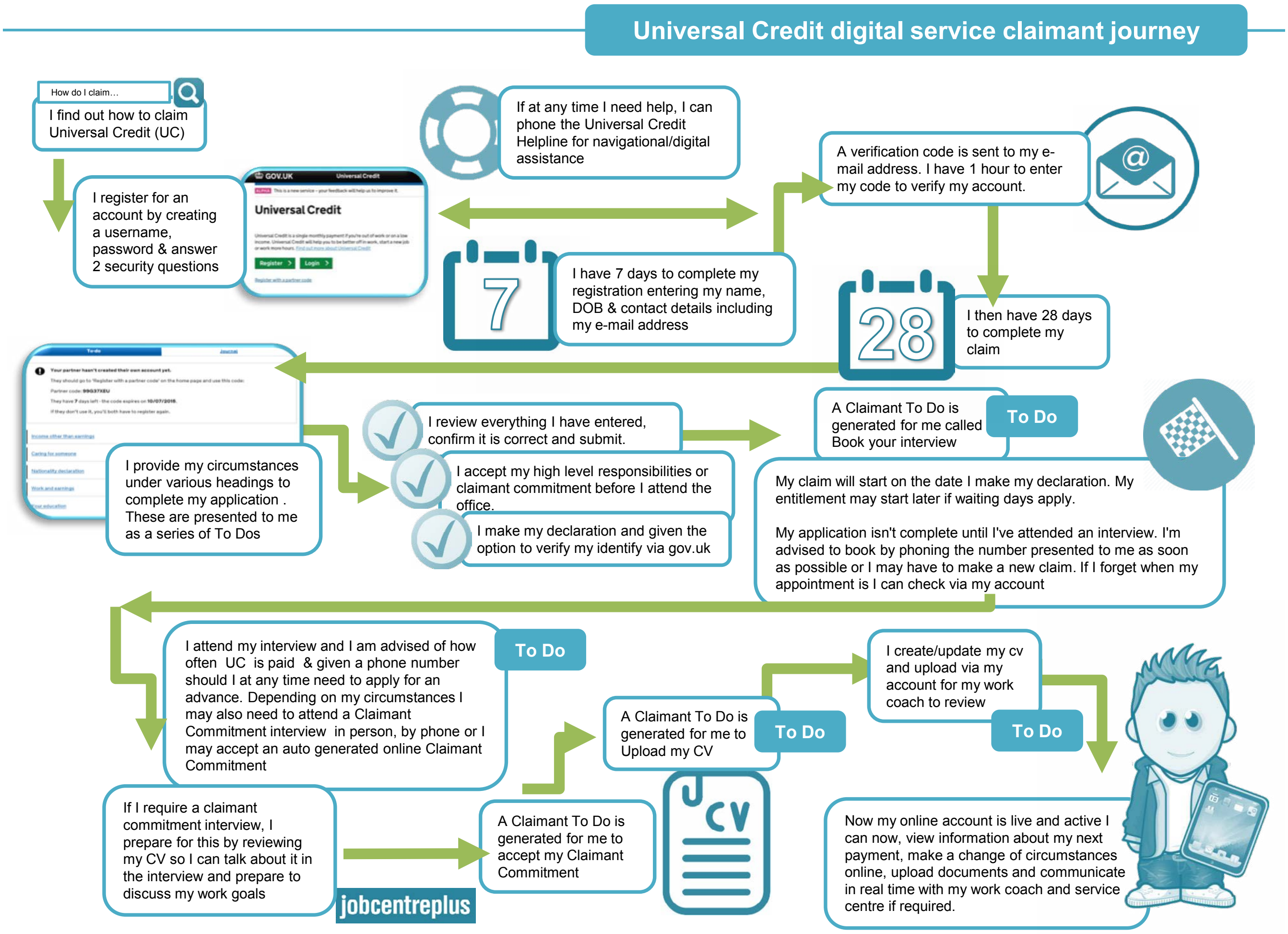


Figure 2: Universal Credit digital service claimant journey

2 House of Commons library https://commonslibrary.parliament.uk/social-policy/welfare-pensions/universal-credit-how-long-are-new-claimants-waiting/

Claiming benefits under special rules: the DS1500

If someone has a terminal illness and can be "reasonably expected to die within the next six months", they are eligible to apply for benefits under special rules. In order to do this, a claimant will be asked to send a factual statement from their doctor to the relevant government department when they make their benefit claim. This statement is called a DS 1500 report.

Depending on the benefit, claiming under special rules has slightly different implications.

Disability Living Allowance / Personal Independence Payments

Under special rules, claimants are not subject to a three month qualifying period before receiving DLA or PIP. On top of this, claimants will automatically qualify for the highest rate of the DLA care component, or the enhanced rate of the PIP daily living component.

Employment Support Allowance

People claiming ESA under special rules will have their claims fast-tracked, and they will be automatically placed in the Support Group. Claimants will also be paid for the first seven days of their claim.

Attendance Allowance

Under special rules, people claiming Attendance Allowance will not be subject to the six month qualifying period, and will automatically receive the highest rate of Attendance Allowance (AA).

Universal Credit

Universal Credit claimants will not have to meet work-related requirements (such as attending work-focused interviews) to keep getting Universal Credit in full. Universal Credit will be paid at a higher rate, as a 'work capability amount' will be included in the award.

The DWP will offer additional support to a claimant who has a DS1500 to assist them in making their claim. DWP guidance indicates that they should receive a personal phone call within a few days of notification of the DS1500.

Where the DWP is aware of a terminal diagnosis, the DWP should telephone the claimant to offer assistance with the claim process. However, the DWP is usually only aware of a diagnosis once the claimants self-certifies their prognosis during the claim process, so any assistance is often too late to assist with the claim itself.

Interviews with support workers indicate that the claim process is much better if a claimant has previously submitted a DS 1500, so that they are eligible to claim under special rules for terminal illness.

Verification

Identity verification is required in order to claim Universal Credit. The verification process uses publicly available data, such as passports, driving licences and credit histories, to prove identity. It is intended that this is carried out online as part of the claim process. However, current IT problems mean that many claimants must verify their claim in person at the local JCP. Information from Verify[3], the company that is responsible for the verification process, reveals that at the end of 2017, 30% of claimants were not able to verify claims online and a further 35% chose not to do so.

If the claimant has indicated that they are terminally ill in the claim process, it is likely that a home visit can be agreed for verification purposes. The claimant must know that this is available and set out their reasons for requesting this. However, if claimants are not aware of their prognosis, a home visit may not be granted and a visit to the JCP may be necessary. Where a claimant has not self-certified as terminally ill, a claimant commitment interview will be required and claim verification can be combined with this.

Claimant commitment interview

The claimant commitment interview is an important part of the Universal Credit process. Unlike ESA, where claimants in the Support Group did not have to have a claimant commitment interview, all claimants for Universal Credit are expected to have an interview unless exceptional circumstances apply. This includes those in the Limited Capability for Work-Related Activity group. For many people living with MND, this presents emotional and physical challenges.

Where a claimant is terminally ill, and this is notified to the DWP through self-certification in the claim process or through a DS 1500, they should fall under the "exceptional circumstances" regulations that mean a claimant commitment interview is not required. This regulation states that[4]:

> *16. A person does not have to meet the basic condition to have accepted a claimant commitment if the Secretary of State considers that—*
>
> > *(a)the person cannot accept a claimant commitment because they lack the capacity to do so; or*
> >
> > *(b)there are exceptional circumstances in which it would be unreasonable to expect the person to accept a claimant commitment.*

3 Minutes from GOV.UK Verify, Privacy & Consumer Advisory Group, Meeting date: 16 November 2017

4 The Universal Credit Regulations 2013

Guidance to DWP decision makers is that terminal illness is considered an exceptional circumstance. The guidance states:

> *J1026 Examples of when exceptional circumstances may apply include:*
>
> 1. *the claimant is incapacitated and in hospital and is likely to be there for weeks*
> 2. *the jobcentre is closed due to an emergency, for example a fire or flood*
> 3. *there is a domestic emergency preventing the claimant from accepting the claimant commitment*
> 4. *the claimant is terminally ill.*
>
> *The list is not exhaustive. When determining whether or not exceptional circumstances apply, the Decision Maker should remember the normal and every date meaning of "exceptional" is "unusual, not typical"*

A footnote to the guidance indicates that the Decision Maker should use the DWP definition of terminally ill (see right). Therefore "exceptional circumstances" are only routinely applied where a DS 1500 has been submitted and the DWP definition of terminally ill has been met.

Terminal illness: definition

Regulation 2 of the Universal Credit Regulations 2013 has the following definition of terminally ill:

"terminally ill" means suffering from a progressive disease where death in consequence of that disease can reasonably be expected within six months;

This prognosis is certified by the DS 1500. The DWP definition of terminally ill is particularly problematic for those living with MND. The DS 1500 requires a medical professional to certify a prognosis that the claimant is likely to die within six months. The progression of motor neurone disease is difficult to determine, and the MND Association advisors we spoke with mentioned that many health professionals are often unsure about whether they can certify a six-month prognosis.

In Scotland, the Social Security (Scotland) Bill was passed in April 2018 and contains a clause which would remove any time qualification for people who are terminally ill. The amendment ensures that definition rests on the clinical judgement of medical professionals to identify when a person is terminally ill. This will come into force when disability benefits are devolved to the Scottish Parliament. The Scottish Government does not have responsibility for Universal Credit and it is unclear how the DS 1500 issued under the new legislation for disability benefits will be incorporated into Universal Credit in Scotland. The Scottish Government has obtained various amendments to Universal Credit regulations for Scotland and it is likely that the new definition of terminal illness will also be incorporated into Universal Credit in Scotland.

Following the change in definition of terminal illness in Scotland, the SDLP deputy leader Nichola Mallon has requested that the Department for Communities in Northern Ireland introduce a similar change.

It is worth noting that Regulation 16 does not limit "exceptional circumstances" to this definition, nor require a DS1500 to have been submitted, or for the person to have self-certified that their condition is terminal, in order for the claimant to be exempted from the claimant commitment interview. MND is a terminal disease and, it could be argued that the statement of the condition on the claim form alone, should be sufficient for the exceptional circumstances regulation to apply.

For many claimants without a DS 1500, a claimant commitment interview will therefore be required. The regulations state that a claimant commitment can be made electronically, by telephone, or in person. Routinely, these are carried out face-to-face at the local JCP although visits can be requested.

Under the Equalities Act the claimant can request "reasonable adjustments" to be made to the claim process to accommodate their disability. This can be used to request that the interview is at an accessible location and at a time that is convenient to any support workers or carers. And, as with making a claim, a home visit can be requested. Where a claimant can visit a JCP, they can be accompanied by someone else. This may be useful for assistance with mobility or communication or ensuring that the claimant understands the commitment.

Interviews with MND support workers identified the appropriateness of questions posed at the claimant commitment interview as a specific weakness in the claim process. The move to Universal Credit means that JCP officers conducting the interview are generic work coaches. Their primary role is to move people into work, or into further work. The GOV.UK website specifically mentions the changed role of the work coach:

"With Universal Credit, you will experience a different type of relationship with your work coach than you may have expected. They will focus on mentoring and coaching you, to help you meet the requirements recorded in your Claimant Commitment. They will support and challenge you to fulfil your potential and help you to raise your expectations of what you can achieve".

The design of the Universal Credit system is work-focused. This is illustrated by a freedom of information request[5] that provides the Government's rationale for requiring an interview for all claimants. It states:

"A personalised approach to labour market activity, together with appropriate sanctions, will encourage and incentivise claimants to take responsibility for preparing for work, finding work and taking up more and better paid work. The Claimant Commitment is at the heart of this personalised approach. Compliance with requirements such as active job search and engagement with advisers, increases the chances that claimants find work more quickly than they would otherwise, but too often in the current system there is a lack of clarity about requirements and consequences. The Claimant Commitment will address this, for the first time setting out all requirements and consequences in one place – ensuring claimants understand what is required."

Claimants with a DS 1500 will not have a claimant commitment interview, but this interview will be required for all those that are terminally ill, but do not have a DS1500. Work coaches are not specifically trained in terminal illness or necessarily sensitive in taking care about judging the suitability of posing work-focused questions to those who are terminally ill.

The claimant commitment for those in the Limited Capability for Work-Related Activity (the equivalent of the old ESA Support Group) only requires them to notify promptly any changes in circumstances. It is therefore more suitably undertaken electronically rather than face-to-face.

Explicit consent

Under legacy benefits, DWP staff were provided with guidance on implicit consent for working with claimant representatives[6]. Implicit consent does not apply under Universal Credit. The DWP argue that this is due to security issues because of the digital nature of the claim and, that as claimants have access to all their claim data through their online journal, they can choose to share this when they wish.

Under Universal Credit, the DWP require explicit consent to receive information, or provide information, to any representative that is not the nominated appointee. The explicit consent rules require that the claimant is specific about what they are authorising someone to deal with on their behalf about, and this must be recorded in their journal. If explicit consent is provided by phone (for example at a three-way phone call), the consent is recorded at the time. The DWP states that, for explicit consent to be given, the claimant must:

- *give consent for your personal information to be shared with the representative*
- *outline what information you want to be disclosed*
- *explain why the information is needed*
- *explain the representative's relationship to you where the representative is your family member or friend*
- *give the name of the representative and the organisation, including the branch where applicable. If you cannot provide the name of the representative, you need to be as specific as possible, for example you should provide the representative's job role or team name within the organisation.*

Explicit consent does not last forever, it usually lasts until either the specific request is completed or the end of the assessment period, after the one in which the consent was given."

This has ramifications for those that require assistance with claim management but are not yet at the stage of requiring an appointee. The claimant will need to request explicit consent for every aspect of the claim they wish their claimant to discuss. And if this is required the following month, they will need to record explicit consent again.

When can the DWP share information?

There are a few instances in which the DWP can share information regarding a Universal Credit claim to someone who isn't an appointee without explicit consent. These are:

- if information is required under a court order
- if a legal gateway applies (eg certain named welfare support activities)
- MPs contacting Universal Credit on their constituent's behalf
- if it is in the public interest (usually from requests by social workers or the police).

This insistence of personal claim management causes specific issues for those with a terminal diagnosis. They will need to

5 Freedom of Information request 2451/2013

6 http://www.gov.uk/government/publications/working-with-representatives-guidance-for-dwp-staff

"self-certify" the diagnosis either through a record of this in their journal or provision of a DS1500. This process cannot be undertaken by others on their behalf, including medical professionals, without explicit consent. This means that if a claimant has a terminal diagnosis that they either do not know about, or do not want to face, this cannot be notified by a representative, or discussed with a representative of the claimant, unless that representative is an appointee. This can prevent the claimant accessing additional claim support and invoking the special rules for the terminally ill.

Work Capability Assessment

If a claimant is too ill to work they will generally need to undergo a Work Capability Assessment (WCA). This assessment determines the support a claimant will receive and their work commitment requirements. For the first 13 weeks after claiming, claimants are placed in the Assessment Phase whilst the WCA is carried out. Once they are assessed, if they are found to have incapacity for work, they are placed in either the Limited Capability for Work (LCW) group, which is the equivalent of the old ESA WRAG group, or the Limited Capability for Work-Related Activity (LCWRA) group, equivalent to the ESA Support group. A claimant placed in the LCW group will have a "work preparation requirement" included within their claimant commitment. A claimant placed in the LCWRA group is exempt from undertaking any work-related activity and receives additional support in their Universal Credit.

Claimants who are terminally ill and have a DS 1500 do not need to have a WCA, as they are automatically placed in the Support Group from the first day of their claim. This means that they will receive the additional LCWRA element of Universal Credit (worth £328.32/month) immediately and will not need to wait for this additional support for 13 weeks whilst in the assessment phase.

If a terminally ill person does not submit a DS1500, they will need to have a WCA. The WCA is the same as under ESA. It is based on assessing the capability of a person, rather than assessing their medical condition. Initially, a claimant completes an assessment form, and provides medical evidence of their condition. The usual route following this is a face-to-face assessment followed by periodic re-assessments.

Since September 2017, if a person is placed in the LCWRA group and the condition is:

- lifelong, and
- the level of function would always meet LCWRA, and
- is an unambiguous condition, and
- has no realistic prospect of recovery.

then the claimant will meet the "severe condition" criteria. This means that they will not be required to attend face-to-face re-assessments for their LCWRA component. However, those placed in LCWRA before September 2017 must have a final re-assessment to be assessed as meeting the severe conditions criteria.

If a claimant with MND does not initially meet the descriptors to be placed in the LCWRA group, re-assessments will continue until such a time that the person meets these descriptors and is placed in the LCWRA group. After that, re-assessments should cease due to the person meeting the severe conditions criteria.

MND is a progressive disease and changes in a person's capability can be rapid. The DWP could consider automatically classifying those with MND as meeting the descriptors for both LCWRA and the severe condition criteria, in order to remove the burden of re-assessments.

Terminal illness – changes under Universal Credit

The predecessor benefit to Universal Credit for those too ill to work is ESA. Under ESA, specialist training is provided to teams dealing with claimants who are terminally ill. There appears to be no equivalent guidance to staff dealing with Universal Credit claims. A Freedom of Information Act request for this guidance ignored this aspect of the request in the reply[7].

The DS 1500 continues to provide a fast-track to benefit support and automatic categorisation into the LCWRA group. However, under Universal Credit and the rules of explicit consent, the claimant must provide this themselves. Unlike the implicit consent in legacy benefit systems, the terminal nature of a claimant's illness can no longer be discussed with a representative. This results in claimants who do not know their prognosis, or do not wish to confront their prognosis, missing out on valuable support.

For organisations that routinely support terminally ill people to undertake the DS 1500 process, the changes around explicit consent to assist in invoking the special rules under Universal Credit is particularly concerning. The MND Association has a network of 22 Care Centres where people living with MND receive this and other kinds of support, so that these changes would have a big impact on the way that MND co-ordinators can work with their patients.

Recommendations

The claimant journey for claimants with MND could be assisted by the following amendments:

- Staff guidance should include recognition of the exceptional nature of progressive terminal conditions, even when the claimant does not state the terminal nature of the condition or the prognosis. This would trigger the equivalent rapid telephone response and offer of support as submission of the DS1500. In particular, the claimant should be made aware that an appointee can discuss their condition if they would prefer not to.
- Progressive terminal conditions should be treated as an exceptional circumstance under regulation 16 of the Universal Credit Regulations 2013. Thus ending the requirement for a claimant commitment interview.
- Home visits should be offered as a matter of course to all those with progressive terminal conditions where claim verification is required. They should not need to hold a DS1500.
- Implicit consent should be accepted for people or agencies that notify the DWP of terminal illness. This would also require training of DWP staff to understand that the prognosis should not necessarily be disclosed to the claimant. This would enable third parties to notify the DWP of a claimant's condition and therefore trigger the special rules.
- Claimants with diseases that have a rapidly progressive nature should be treated in the same manner as those that have submitted a DS 1500: the claimant should be automatically assigned to the LCWRA group and receive additional support.
- The DWP should change the definition of terminally ill to enable it to encompass progressive terminal diseases where prognosis is problematic, such as MND. In particular, the "reasonable expectation of death in six months" should be omitted from both the DWP definition of terminal illness and the requirement for issue of the DS 1500. Defining the terminal nature of a disease should rest wholly with medical professionals.

7 https://www.whatdotheyknow.com/request/436108/response/1091823/attach/3/4245%20IR%20628%20Attachment.pdf?cookie_passthrough=1

The implications of Universal Credit to those with MND: benefit support

Any change of benefit scheme will have implications for claimants; there will always be some that lose support and some that gain support. Initially the introduction of Universal Credit was intended to be cost neutral, with support moving from those out of work towards those in work. Since the inception of Universal Credit, cost savings have been made with the result that most claimants will lose support when they migrate to Universal Credit. In general:

- Those in receipt of disability benefits will lose support. In many cases losses will be significant.
- Self-employed households will lose support.
- Most lone parents will lose support.
- Households in employment will gain support (if they are not in receipt of disability benefits or lone parents).

The key issues for claimants with MND are shown below.

Removal of disability premiums

Legacy benefits contained additional amounts (disability premiums) for claimants living with disability. There is no equivalent of these additional amounts in Universal Credit. This will result in a significant reduction in benefit for the majority of those receiving DLA/PIP who move to Universal Credit.

These disability premiums (2018/19) are shown below.

Premium	Amount £/week	Recipients
Disability premium £33.55/week	£33.55	Awarded to claimants in receipt of DLA/PIP
Enhanced disability premium	£16.40	Awarded to claimants with highest level of living/care component under DLA/PIP
Severe disability premium	£64.30	Awarded to claimants with the highest level of living/care component under DLA/PIP, with no other adults in the household, and nobody receives Carer's Allowance in respect of them.

Figure 3: Disability premiums available under legacy benefits

Universal Credit does contain an additional amount for those in the Limited Capability for Work-Related Activity group (the equivalent of the ESA Support group) which offsets some of these losses. The most severely affected are therefore those in the Limited Capability for Work group (the equivalent of ESA WRAG) who are in receipt of DLA/PIP, and those in receipt of DLA/PIP who are not in receipt of any ESA but receive other benefits (such as IS or JSA).

Income-based Employment Support Allowance and Universal Credit

Income-based Employment Support Allowance (ESA)

Under legacy benefits, people that receive ESA undertake a Work Capability Assessment and will be placed in either of the following groups:

Work-Related Activity Group:

- The claimant has regular interviews with an adviser in order to prepare for work.
- £73.10/week.

Support Group

- The claimant does not have regular interviews, as they are not expected to re-enter employment.
- £110.75/week, plus enhanced disability premium worth £16.40/week.

If the claimant also receives DLA or PIP, their ESA may be increased by disability premiums.

Whilst the Work Capability Assessment is underway, the claimant is placed in an Assessment Phase and receives a fixed amount of ESA.

Universal Credit

Under Universal Credit, claimants who are too ill to work are still assessed through a Work Capability Assessment, and placed into either of two groups that mirror those under legacy benefits. The groups are:

- Limited Capability for Work (LCW) – equivalent to ESA WRAG.
- Limited Capability for Work-Related Activity (LCWRA) – equivalent to ESA Support group.

The amounts that claimants get in each group is slightly different, due to changes in the allowances that make up Universal Credit plus the disappearance of several disability premiums that were available under legacy benefits. These premiums are shown in figure 3.

Most claimants with MND who are in receipt of PIP will be in the LCWRA group. They will be affected by the loss of premiums but not to the same extent as those that are in the LCW group. If the person in the example above was in the LCWRA group, then support would reduce from £1200.24 to £1017.04. A reduction of £183.20/month. This is significant reduction in income but much less than if they received PIP but were not in the LCW group.

Example

A single person, receiving PIP (no ESA group)

Legacy benefits (ESA assessment and Housing Benefit) £811.47/month	
Universal Credit	£317.82/month
A reduction in support of	£493/month

Disabled child premium

Universal Credit does contain a disability element for children. Under legacy benefits additions for child disability are included in the parents out-of-work benefits (JSA, ESA and IS) and in Child Tax Credits. The combination of these is higher than the child disability element within Universal Credit.

Example

A couple with a child receiving the highest level of DLA

Legacy benefits (JSA and Child Tax Credits)	£1184.31/month
Universal Credit	£1114.42/month
A reduction in support of	£69.69/month

The carer's element

Universal Credit includes an additional amount for carers. This is set at a similar amount to the carer's premium under legacy benefits.

The position for carers who are also engaged in other work is better under Universal Credit. Under legacy benefits, a person would no longer be entitled to out-of-work benefits as a carer if they worked for more than 16 hours. Under Universal Credit, there is no earnings limit. The carer's element can still be included so long as the carer is still caring for at least 35 hours a week and meets the other conditions of eligibility.

The introduction of Universal Credit for carers could have an impact on the benefits of the person being cared for if that person still receives legacy benefits. This will happen if the person being cared for receives benefits which include the severe disability premium. This premium is an additional amount of benefit within ESA, IS, JSA and HB awarded to those with severe disability who live alone. If a carer receives the carer's element under Universal Credit, the person being cared for will lose their severe disability premium. If the carer was still receiving legacy benefits (Income Support) then the severe disability premium would only be lost if the carer claimed Carer's Allowance. Many carers chose to not claim Carer's Allowance as this is worth less than the severe disability premium. This choice is not available under Universal Credit.

There is no equivalent of the severe disability premium in Universal Credit. Therefore, if the person being cared for is in receipt of Universal Credit, it does not matter which benefit the carer claims (ie Income Support under legacy benefits or Universal Credit).

Limited Capability for Work-Related Activity

Universal Credit includes an additional element for claimants with Limited Capability for Work-Related Activity (LCWRA). This is the equivalent of the ESA support group.

The additional element for claimants in the LCWRA group is higher than the equivalent additional support group component in ESA. Therefore, a claimant who is in the LCWRA group, and is not affected by the cessation of disability premiums, will usually be better off under Universal Credit.

Example

A single person with LCWRA (ESA Support)

Legacy benefits (ESA)	£550.92/month
Universal Credit	£646.14/month
An increase in support of	£95.22/month

Since April 2017, there is no additional support for those in the Universal Credit Limited Capability for Work (LCW) group or the equivalent ESA WRAG. For claimants in this group, benefit support remains the same under Universal Credit as under legacy benefit systems.

The majority of PIP claimants with motor neurone disease should receive PIP at the highest level and will be placed in the LCWRA group. For claimants in this position, the increased support for the LCWRA element under Universal Credit is offset by losses incurred through removal of disability premiums. In general, this will result in a net loss of support.

Example

A single person with LCWRA (ESA Support) and PIP

Legacy benefits (ESA)	£1200.24/month
Universal Credit	£1017.04/month
A reduction in support of	£183.20/month

Work allowances

Work allowances are the amount a claimant can earn before benefits are affected. These were termed earnings disregards under legacy benefits.

Under Universal Credit, work allowances have been reduced for those with limited capability for work (LCW and LCWRA). The work allowance is £198/month for those without housing costs and £409/month for those with housing costs. The equivalent amount under ESA (the permitted earnings limit) is £542.49/month.

Although Universal Credit contains lower work allowances than ESA, the higher retention of earnings under Universal Credit will usually offset at least part of this loss.

Example

Claimant earning £500/month working 12 hours/ week. LCW (ESA WRAG)

Legacy benefits	£766.77/month
Universal Credit	£734.43/month
A reduction in support of	£32.34/month

Withdrawal of benefit with earnings

Universal Credit enables all claimants to retain 37p for each pound earned. An increase in earnings will therefore always result in increased household income. Under legacy benefits (ESA), benefit is reduced by an amount equal to the net amount earned. Most part time workers are therefore better off under Universal Credit.

However, claimants with MND will have limited capability for work and so face a smaller work allowance under Universal Credit. The lower withdrawal of benefit under Universal Credit will only increase household income if earnings are below the Universal Credit work allowance (either £192/ month if the claimant has housing costs or £409/month if there are no housing costs). Beyond this, a claimant would be better off under legacy benefits, until they exceeded the ESA work allowance.

Working hours

Unlike out-of-work legacy benefits, eligibility to Universal Credit is not dependant on the number of hours worked. Under legacy benefits, Working Tax Credit ends if a person works less than a set number of hours (this is 16, 24 or 30 hours, dependant on the household circumstances). If the person works fewer hours they would need to end the claim for Working Tax Credit and move to other benefit support, such as ESA, JSA or IS. This would necessitate making a new claim with a different agency (DWP rather than HMRC). Universal Credit provides more flexibility, allowing people to start claiming Universal Credit sooner and increase their support more gradually. This is useful for those with MND as it facilitates changing working hours as the condition progresses.

A 16-hour rule is still retained for defining if a person has limited capability for work or not. If a person works more than 16 hours they are deemed capable of work and will no longer be classified as having limited capability for work. For those in the LCWRA group, this will result in the loss of the LCWRA additional support component.

However, under Universal Credit, if a person receives PIP and has LCWRA, there is no limit to the hours that can be worked. The claimant can work as many hours as they wish whilst still being classified as LCWRA. The DWP will make an individual decision as to whether the person retains limited capability for work.

As the majority of those with MND receive PIP and are in the LCWRA group, this provides greater capability to continue working where this is possible.

Self-employment

Under legacy benefits, the net profit of self-employment determines income for benefit purposes. Under Universal Credit, the self-employed will be assessed as earning a notional income (the Minimum Income Floor), calculated as the national minimum wage multiplied by the hours that the person would be expected to work. For most claimants without caring responsibilities or limited capability for work, this would be the equivalent of the national minimum wage for 35 hours/week. As most self-employed claimants earn less than this amount, they will face significant losses when they move to Universal Credit.

If a person has MND they are unlikely to be affected by these rules. If a person has limited capability for work, there will be no expectation of work and so the Minimum Income Floor will not apply.

Capital

Out-of-work legacy benefits (ESA, IS and JSA) and Universal Credit share the same rules regarding capital. Capital below £6,000 is ignored and if capital is above £16,000 there is no eligibility to benefit support. Capital between these amounts produces a notional income that is taken into account for benefit assessment purposes.

The key difference between legacy benefits and Universal Credit is that there is no capital limit for Tax Credits. Therefore, a person with capital over £16,000 could still receive Child Tax Credits under legacy benefits but would receive no support at all under Universal Credit.

Example

A person with two children with £25,000 savings, receiving interest of £750/annum

Legacy benefits (Child Tax Credits)	£508.75/month
Universal Credit	£0.00/month
A reduction in support of	£508.75/month

The entitlement cut-off to Universal Credit if savings are over £16,000 is particularly relevant if a person with MND were to receive a Critical Illness or Terminal Illness lump sum payment.

Insurance

Lump sum payments of Critical Illness insurance and Terminal Illness insurance are treated as savings under both legacy benefits and Universal Credits. If the amount is over £16,000 a person with a child may still receive Child tax Credit under legacy benefits (as the interest is taken into account rather than the capital) but would not be eligible for any support under Universal Credit.

If insurance is paid as an income, it can be treated differently under Universal Credit than under legacy benefits, depending on the type of insurance.

If income insurance is paid by the employer (Group Income Protection, or GIP) it is treated as earned income under both benefit systems. A person would therefore usually be better off under Universal Credit than ESA as they would retain a higher proportion of earned income.

Individual income protection (IIP) is treated differently under Universal Credit than under legacy benefits. Under legacy benefits it is treated as earned income and so some of it will be ignored when benefits are calculated (through the earnings disregard). Under Universal Credit, income from individual protection is treated as unearned income and so all of it is taken into account. Under both ESA and Universal Credit the payment would reduce benefit income pound for pound. However, there would be a lower reduction in support under legacy benefits as an earnings disregard would apply.

If a person received individual income protection and was in receipt of tax credits, the loss under Universal Credit would be greater, as tax credits would be reduced by a percentage of the income (the taper). Under Universal Credit, the reduction would be pound for pound.

Support for Mortgage Interest (SMI)

Both legacy benefits and Universal Credit provide Support for Mortgage Interest (SMI). The amount of support provided is calculated in the same manner under both benefits systems.

Eligibility differs between benefit systems. All those in receipt of means-tested ESA are eligible for mortgage support but under Universal Credit this is only available to those without any earned income. In addition, a person must have been in receipt of Universal Credit for nine months before they can apply for SMI.

Crucially, from April 2018, SMI will become a loan for every household currently in receipt of SMI and for every new claim. The loan is repayable with interest once the property has been sold or the claimant dies. As at March 2018 there was low take-up of this loan. This is partially due to the difficulties encountered by agencies of the DWP in contacting householders, and a reluctance to take up the loan amongst those that have been contacted. Only 60% of those eligible for the loan have been successfully contacted and of these, only 24% have opted to take the loan[8]. This means that many owner occupiers will no longer have the means to pay their mortgage.

People living with MND and with a mortgage will now be unable to receive benefit support to meet these costs. They will have the option to take out a loan if they are no longer working, as long as they have been in receipt of Universal Credit for nine months. Many of those with MND will not live for nine months following diagnosis and so will not be eligible for any mortgage support. If the claimant opts to take out the loan, once they pass away the repayment will fall to their family or their estate.

Recommendations

- The capital cut-off limits will mean reduced support for those moving from tax credits to Universal Credit who have capital over £16,000. This could particularly affect those who receive lump-sum insurance payments. It would assist those with MND if some of these awards could be disregarded for Universal Credit assessment purposes.
- Individual income protection regular payments should be treated as earned income under Universal Credit, as under legacy benefits.
- The time limit before a claimant can apply for mortgage interest support loans should be reduced from the current nine months for those with progressive terminal illness.

8 Conversion of Support for Mortgage Interest from a Benefit into a Loan: claimant communication and intention to take up a loan, DWP Official Statistics, 23 March 2018

Other benefits

The introduction of Universal Credit will generally have no impact of most non-means tested benefits. Council Tax Support is a means tested benefit and may be affected by Universal Credit. The main other benefits relevant to a person with MND are shown below.

Carer's allowance

Carer's Allowance remains the same under Universal Credit. It is treated as unearned income, and so reduces benefit support pound for pound under legacy systems and Universal Credit.

Under legacy benefits, if someone's carer received Carer's Allowance then that person would not be eligible to receive the severe disability premium. They would need to assess whether the Carer's Allowance received is greater than the person being cared for would lose through the premium. However, this is not the case under Universal Credit. As there are no disability premiums under Universal Credit, whether a carer receives Carer's Allowance or not will have no impact on the benefits of the person being cared for.

Contributory ESA and Contributory JSA

Contributory ESA (C-ESA) and Contributory JSA (C-JSA) remain under Universal Credit. They are essentially the same as under legacy benefits but are termed "new-style ESA" and "new-style JSA". Under both legacy benefits and Universal Credit, eligibility relies on national insurance contributions. A partner's income is not taken into account and savings are ignored. Any means-tested benefit that is awarded (either ESA or Universal Credit) is reduced pound for pound by the amount of contributory benefit received.

The key difference between the new benefits and old C-ESA and C-JSA is that new-style ESA and new-style JSA fall under the conditionality regime of Universal Credit.

Claimants are currently reporting difficulties with claiming new-style ESA. They are directed towards the Universal Credit helpline but this does not offer options for contributory benefits and the procedures for assessment do not seem to be embedded. This needs to be rectified as a matter of urgency.

Passported benefits

As Universal Credit is designed to cover a wider income range than legacy out-of-work benefits, it no longer acts as a passport to other support such as free school meals and free prescriptions. Under Universal Credit, access to other support is now generally set with reference to income thresholds.

Council tax reduction

Since 2012 local authorities have had the power to set local council tax support schemes for working age households (LCTRS). Support for pension age households remains under the Council Tax Benefit legislation (CTB). A default scheme is provided for councils that fail to set their own scheme, which is similar to the CTB scheme for pensioners.

Most councils set a scheme based on the CTB regulations and introduced cost-saving measures such as minimum payment amounts or reduced capital cut-offs. The CTB regulations have been updated to include treatment of Universal Credit and these changes have been incorporated into most local council tax support schemes.

The changes mean that, in most local authority areas, the assessment of income for council tax support is different if the claimant receives Universal Credit or legacy benefits. The amended regulations result in little difference in award if a claimant is not working as they will receive maximum support under both schemes. However, where a claimant has earned income, they are likely to receive lower local council tax support. This is because the claimant retains more earned income under Universal Credit and this reduces their council tax support. In addition, the Universal Credit calculation is used as an assessment of needs to which income is compared. Where a claimant has lost disability premiums due to the move from legacy benefits to Universal Credit, this lower "needs" is reflected in the amount of council tax support received.

Claimants in receipt of disability benefits (DLA/PIP) who are working are likely to receive reduced local council tax support under Universal Credit than under legacy benefits.

Social care support

The introduction of Universal Credit will not affect access to social care support. This will be accessed in a similar manner as under legacy benefits.

Case Studies

People with MND that claim Universal Credit are likely to be affected by a combination of the changes and issues outlined above. Furthermore, there is no single journey through the benefits system for somebody with MND. The impact that Universal Credit has will depend on household circumstances, type of disability benefit and type of means-tested benefits.

For these reasons, this section illustrates the complex impacts of Universal Credit through four case studies:

- The first case study is a single person living with MND who is receiving disability benefits, and is classed as having limited capability for work.
- The second case study is a family, where one member has MND and their partner has become their carer.
- The third case study is a single person with MND, for whom a relative occasionally cares, and who owns their own home.
- The fourth and final case study is a couple with three children, where one person has MND and has an external carer, but their partner continues to work

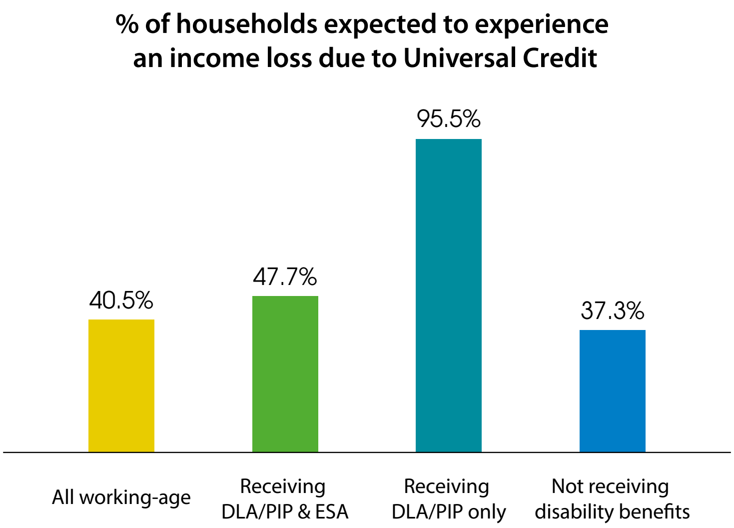
Each case study includes an individual link to the Benefit and Budgeting Calculator.

It should be noted that, because Universal Credit will only become available to working-age households, none of the case studies look at people of pension-age. For people of pension age with MND, the benefits that will be available to them will remain the same as currently.

In order to provide a clearer indication of the real monetary impact that Universal Credit could have on people living with MND, where possible figures are given on the average actual impact of Universal Credit on households receiving different disability benefits. This is contained within orange boxes. The analysis is taken from Family Resources Survey data for 2015/16[9], a comprehensive annual dataset of households in Britain and their circumstances.

Data analysis from Family Resources Survey

As the graph to the right shows, households receiving disability benefits are more likely than those not receiving them to see an income loss due to Universal Credit. This is especially pronounced in the case where somebody receives DLA/PIP only. Underlying figures can be found in Appendix 3.



9 Family Resources Survey data available to download here: https://www.gov.uk/government/collections/family-resources-survey--2

Case Study 1: Ahmed

Ahmed is single and has MND. He is claiming the highest component of Personal Independence Payment (PIP). On top of this, Ahmed is classed as having Limited Capability for Work. This classification equates to the Work-Related Activity Group (WRAG) of Employment and Support Allowance.

In order to make an accurate benefit assessment, we have made several assumptions about other aspects of Ahmed's household circumstances. These are listed in the Annex.

Under the current benefits system, Ahmed would receive ESA of £666.20/month. Together with Housing Benefit, Council Tax Support and PIP, his take-home income would be £1,713.81/month. Figure 1 below shows the different benefits that Ahmed would be entitled to under the current benefits system.

- Single, claiming highest rate of PIP (mobility and daily living).
- Aged 43.
- Limited capability for work.
- Potentially able to work a few hours a week from home.
- Rents a room for £340/month in Craven, Yorkshire.

Current system

ESA (based on income)	£666.20	Child Benefit	£0.00
Pension Credit	£0.00	PIP / DLA	£629.80
Working Tax Credits	£0.00	Council Tax Support	£77.81
Child Tax Credits	£0.00	Net earnings	£0.00
Housing Benefit	£340.00	Contributory ESA/JSA & other income	£0.00

Figure 4: Ahmed's benefit entitlements under the current benefits system

Figure 5 shows the breakdown of Ahmed's ESA entitlement under the current system. This is Ahmed's personal allowance – it is not intended for housing costs. It consists of a basic allowance and two disability premiums. These three make up the total ESA entitlement.

ESA (based on income)

Step 1: Calculate Applicable Amount

Lone parent or ESA allowance	£ 316.77
Enhanced Disability Premium	£ 71.01
Severe Disability Premium	£ 278.42
Maximum Entitlement	£ 666.20

Step 2: Calculate income

Total income for assessment	£ 0.00

Step 3: Calculate Award

Income is deducted from the applicable amount

Applicable Amount	£ 666.20
Minus total income for assessment	£ 0.00
AWARD	£ 666.20

Figure 5: Calculation of Ahmed's ESA, under the current system of benefits

Case Study 1: Ahmed

Under Universal Credit, Ahmed's personal allowance and housing support are combined into one benefit. Within Universal Credit there is no equivalent of the two disability premiums. This means that, under Universal Credit, Ahmed's take-home income would be £348.38/month less than under the current benefits system. This comparison can be seen in Figure 6, below.

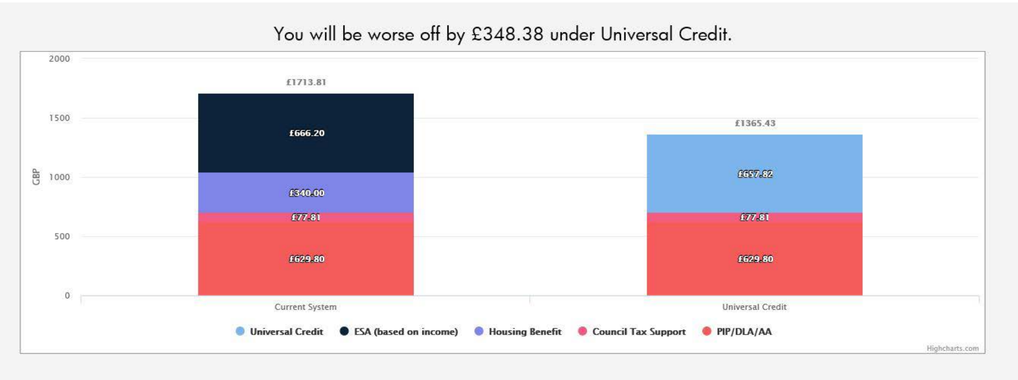


Figure 6: Comparison of Ahmed's take-home income, current system vs. Universal Credit

Data analysis from Family Resources Survey

Analysis of FRS data suggests that around 71,000 households in Britain are in a situation similar to Ahmed's, in that they receive some form of DLA and are in the ESA WRAG group. Like Ahmed, these are households that are likely to lose several disability premiums under Universal Credit, and so could be significantly worse off. Under Universal Credit, 59.3% of these 71,000 households will experience an income loss due to Universal Credit, compared to 40.5% of all working-age households.

What if Ahmed was working 15 hours/week?

If Ahmed had moved from full time work to working 15 hours/week at £10/hour, the difference in his entitlements between the current system of benefits and Universal Credit would be smaller.

This is because, when working 15 hours/week, in the current system of benefits he would hit the "cliff-edge" in eligibility for ESA, so that the comparison to Universal Credit is more favourable. Ahmed's earnings at this point would be too high for him to qualify for ESA. He would instead be entitled to Jobseekers Allowance (JSA), where just the first £86.67/month of his earnings are disregarded. This makes his out of work entitlement just £102.87/month, on top of his Housing Benefit of £340.00/month. Under Universal Credit, he would receive an award of £369.28/month, of which £340.00 is his housing element.

Besides this, in the Universal Credit scenario Ahmed's Council Tax Support would reduce, from £77.81/month to £5.52/month. Council Tax Support (CTS) is calculated according to a localised means-tested scheme, which compares Ahmed's income to an amount corresponding to his needs. While Ahmed is receiving legacy benefits, CTS is calculated such that his income does not exceed his "needs", and therefore he would receive the maximum amount of CTS available to him (£77.81/month). However, under Universal Credit, his "needs" are considered to be lower (due to the disappearance of the aforementioned disability premiums), whilst all his earnings are taken into account. This means that Ahmed's income exceeds his needs, and £72.29/month of potential CTS support is tapered away, which leaves his CTS award at £5.52/month. Again, a full breakdown of how CTS is calculated for Ahmed once he goes onto Universal Credit versus the current benefits system is provided in the Annex.

Case Study 1: Ahmed

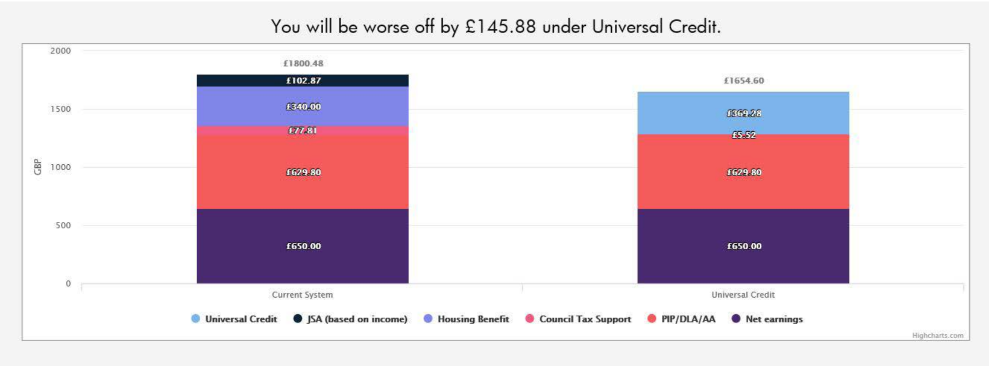


Figure 7: Ahmed's take-home income if he were to work 15 hours/week, current system vs. Universal Credit

What if Ahmed reduced his hours to 10 hours/week?

If due to the progression of MND Ahmed reduced his hours to 10 hours/week at £10/hour, his shortfall under Universal Credit (when compared to Universal Credit) would be much higher.

This is explained by the fact that Ahmed's earnings at this point would still mean he qualifies for ESA, so that he is effectively on the other side of the "cliff-edge". In this scenario, whereas under the current system all of his earnings would have been disregarded, under Universal Credit just his first £192.00 are disregarded. Combined with the disappearance of the disability premiums mentioned earlier, this would leave Ahmed's Universal Credit entitlement at £505.78/month, of which £340.00 is the housing component. This compares to an ESA award of £666.20/month (the same amount as if he wasn't working) and Housing Benefit of £340.00/month under the current system of benefits. A full breakdown of how Universal Credit would be calculated if Ahmed were working 10 hours per week, earning £10/hour, is given in the Annex.

On top of this, Ahmed's Council Tax Support would reduce, although by less than if he worked 15 hours (from £77.81/month in the current system of benefits to £21.56/month). In this case, Ahmed's income exceeds his needs such that £56.26/month of potential CTS support is tapered away, which leaves his CTS award at £21.56/month. Again, a full breakdown of how CTS is calculated for Ahmed once he goes onto Universal Credit versus the current benefits system is provided in the Annex.

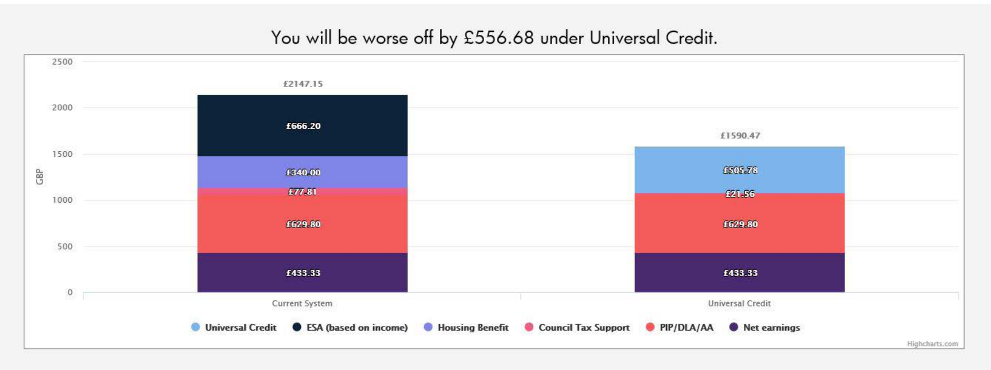


Figure 8: Ahmed's take-home income if he were to work 10 hours/week, current system vs. Universal Credit

Case Study 1: Ahmed

Taken together, if Ahmed were working 10 hours/week at £10/hour and moved over to Universal Credit, his take-home income would reduce from £2,147.15/month to £1,590.47/month, a £556.68/month shortfall.

If Ahmed decreased his working hours from 15 to 10 hours/week under the current system of benefits, his take-home income would actually increase, due to his eligibility to claim ESA. However, under Universal Credit, the same reduction in hours would cause Ahmed's take-home income to decrease slightly, from £1,654.60/month to £1,590.47/month. The overall picture is mixed. Whilst Universal Credit generally means that changes in working hours are reflected in gradual changes in benefit, in this particular instance Ahmed would find himself comparatively much worse off under Universal Credit than under the current system of benefits.

Key points from Ahmed's case:

- As Ahmed is in the Work-Related Activity Group (WRAG) of Employment Support Allowance, under Universal Credit he loses several disability premiums, reducing his take-home income substantially.
- Households that lose benefit under Universal Credit due to removal of disability premiums are likely to also face reduced Council Tax Support.
- If Ahmed were working 10 hours/week, the income shortfall would be even greater, due to a reduction in work allowances under Universal Credit plus reductions in how his Council Tax Support (CTS) is calculated.
- However, if Ahmed changes his working hours, under Universal Credit his support is increased or tapered away gradually, and he would not face the cliff-edges he would face under the current system of benefits.

Case Study 2: Beth and Carl

Beth and Carl are a couple with two children. Beth is living with MND, while Carl has given up work to become Beth's carer, and is claiming Carer's Allowance. Both are under 25.

Under the current system of benefits, Beth and Carl would have a take-home income of £2,833.99/month. As is shown below, in Figure 9, this is made up of a range of benefits.

- Beth is out of work, receives highest rate of PIP (mobility and daily living), She is placed in the ESA Support Group and the equivalent UC category (Limited Capability for Work-Related Activity).
- Carl is Beth's full-time carer, receives Carer's Allowance.
- Two children, aged three and five.
- Rent a three bedroom property, for £480/month.
- Live in Cornwall.

Current system

Income support	£682.70	Child Benefit	£149.07
Pension Credit	£0.00	PIP / DLA	£629.80
Working Tax Credits	£0.00	Council Tax Support	£103.75
Child Tax Credits	£508.75	Net earnings	£0.00
Housing Benefit	£480.00	Contributory ESA/JSA & other income	£279.91

Figure 9: Benefits that Beth and Carl would be eligible for, under the current system of benefits

Income support

Step 1: Calculate Applicable Amount

Couple allowance	£ 497.68
Disability Premium	£ 206.97
Enhanced Disability Premium	£ 101.97
Carer Premium	£ 155.99
Maximum Entitlement	£ 962.62

Step 2: Calculate income

Non-earned income	£ 279.91
Minus disregarded income	£ 0.00
Non-earned income for assessment	£ 279.91
Total income for assessment	£ 279.91

Step 3: Calculate Award

Income is deducted from the applicable amount

Applicable Amount	£ 962.62
Minus total income for assessment	£ 279.91
AWARD	£ 682.70

On top of a PIP entitlement of £629.80/month, Beth and Carl receive Child Benefit and Child Tax Credits, worth £149.07/month and £508.75/month respectively. Carl's Carer's Allowance is £279.91/month, while Council Tax Support is the maximum amount Beth and Carl could receive, at £103.75/month. Housing Benefit is enough to cover rent of £480.00/month. Finally, Beth and Carl receive an out of work entitlement, Income Support, of £682.70/month. As is shown in Figure 10, to the left, this is actually less than their maximum entitlement. This is because Carl's Carer's Allowance, of £279.91/month, is fully taken into account and deducted to arrive at the final figure.

Figure 10: Calculation of Income Support for Beth and Carl, under the current benefits system

Case Study 2: Beth and Carl

Under Universal Credit, Beth and Carl's Child Tax Credits, Income Support and Housing Benefit are wrapped up into a single payment, a Universal Credit award of £1,588.81/month. However, Universal Credit for Beth and Carl is calculated using a different combination of premiums and components. Specifically, whereas under the current system Beth and Carl's Income Support included a Couple Allowance worth £497.68/month (see Figure 10), under Universal Credit the equivalent component is an Adult Allowance worth £395.20/month (see Figure 11). There are also slight differences between the disability premiums under the current system and the equivalent Limited Capability for Work-Related Activity component under Universal Credit, with the latter being slightly more generous. These slight differences mean that, in terms of take-home income, Beth and Carl would actually be £82.65/month worse off, as is shown in Figure 12 below.

Step 2: Calculate Maximum Universal Credit

This is made up of elements based on household circumstances

Adult	£ 395.20
Child	£ 508.75
Limited capability for work-related activity	£ 328.32
Carer	£ 156.45
Housing	£ 480.00
Maximum Universal Credit	£ 1868.72

Figure 11: How the maximum Universal Credit award is calculated for Beth and Carl

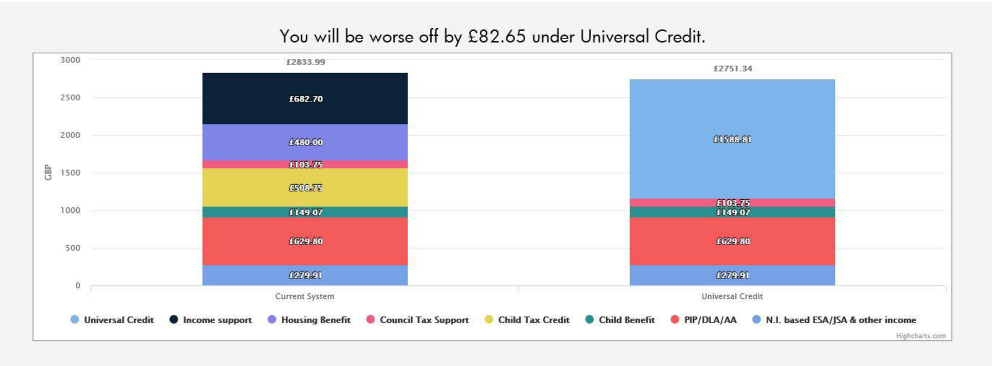


Figure 12: Beth and Carl's take-home income under the current system of benefits, vs Universal Credit

Case Study 2: Beth and Carl

What if Beth and Carl were receiving other income, such as Statutory Sick Pay from Beth's previous employer?

In the case that Beth's previous employer paid her Statutory Sick Pay (SSP) at £387.18/month, the transition to Universal Credit would leave Beth and Carl with a bigger shortfall in income. While under the current benefits system receiving SSP would make no difference to Beth and Carl's take-home income, under Universal Credit they would be £199.59/month worse off. This compares to the shortfall of £82.65/month seen above, where Beth isn't receiving SSP.

This is because if Beth is receiving SSP, under Universal Credit she will lose the Limited Capability for Work-Related Activity (LCWRA) component (an add-on that would make the maximum amount of Universal Credit she could receive higher). Figure 13, below, shows this difference in how the maximum amount of Universal Credit differs when Beth doesn't receive SSP, and when she does.

Step 2: Calculate Maximum Universal Credit

This is made up of elements based on household circumstances

Adult	£ 395.20
Child	£ 508.75
Limited capability for work-related activity	£ 328.32
Carer	£ 156.45
Housing	£ 480.00
Maximum Universal Credit	£ 1868.72

Step 2: Calculate Maximum Universal Credit

This is made up of elements based on household circumstances

Adult	£ 395.20
Child	£ 508.75
Carer	£ 156.45
Housing	£ 480.00
Maximum Universal Credit	£ 1540.40

Figure 13: How Beth and Carl's maximum Universal Credit is calculated if Beth doesn't receive SSP on the left, and if she does on the right.

It is worth noting that, whereas under the current system of benefits every £1 earned above the work allowance is £1 in employment support taken away, under Universal Credit for every £1 earned above the work allowance 63p are taken away from the award. Support is withdrawn more gradually in order to incentivise an increase in hours worked. Because SSP is treated as earnings, this means that for every £1 in SSP received that exceeds the work allowance, Beth and Carl actually keep 37p of their benefits. In this way, Universal Credit is beneficial to Beth and Carl. However, this is not enough to counteract the negative impact of removing the LCWRA component from the calculation of Universal Credit. The result is that, in terms of take-home income, Beth and Carl are overall more worse off if they receive SSP under Universal Credit, as shown in Figure 14 below.

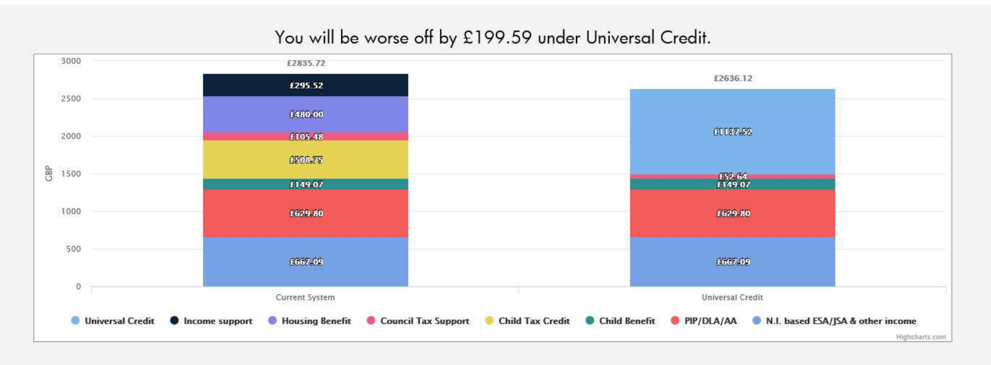


Figure 14: Beth and Carl's take-home income under the current system, vs Universal Credit

Case Study 2: Beth and Carl

What if Beth and Carl were receiving contributory benefits instead of income-based benefits?

If Beth and Carl had previously paid enough National Insurance to qualify for contributory benefits, then their entitlement under the current system of benefits would be slightly higher due to differences in how Carl's Carer's Allowance is considered to calculate contributory benefits. However, under Universal Credit, whether Beth and Carl claim income-based or contributory benefits would make no difference to their final household income. This means that the income shortfall between the current system and Universal Credit is slightly lower if Beth and Carl were claiming contributory instead of income-based benefits.

Key points from Beth and Carl's case:

- Beth and Carl are **worse off under Universal Credit, due to a difference in the components that make up their award**, however they are more protected than if Beth was in the WRAG of ESA
- **If Beth claimed SSP, she would lose eligibility to the LCWRA component of Universal Credit, making her worse off** than if she didn't claim SSP; Beth and Carl would need to weigh up the benefits of retaining SSP versus being eligible for the LCWRA
- If Beth and Carl claimed contributory benefits instead of income-based, the shortfall when transferring over to Universal Credit would be slightly smaller.

Case Study 3: Diane

Diane is single and lives in her own home. She is living with MND and has a relative that cares for her. The relative receives Carer's Allowance.

Under the current benefits system, Diane would receive £768.42/month in ESA. This includes a £217.50/month loan to help her pay off her mortgage. On top of this, she receives £629.80/month in PIP, and £67.63/month in Council Tax Support (CTS).

Diane would actually be better off if her carer didn't claim Carer's Allowance. Under the current benefits system, if Diane's carer receives Carer's Allowance then Diane's ESA does not include the severe disability premium, worth £278.42/month. Diane's ESA would increase by this amount if her Carer wasn't claiming Carer's Allowance. This is shown in Figure 15, below.

- Single, receiving highest rate of PIP (mobility and daily living).
- ESA support.
- Has a relative that cares for her, receiving Carer's Allowance.
- Owns her own home, £100k of mortgage outstanding.
- Lives in Croydon, Greater London.

ESA (based on income)

Step 1: Calculate Applicable Amount

Lone parent or ESA allowance	£ 316.77
Enhanced Disability Premium	£ 71.01
ESA Support	£ 163.14
Housing (mortgage)	£ 217.50
Maximum Entitlement	£ 768.42

Step 2: Calculate income

Total income for assessment	£ 0.00

Step 3: Calculate Award

Income is deducted from the applicable amount

Applicable Amount	£ 768.42
Minus total income for assessment	£ 0.00
AWARD	£ 768.42

ESA (based on income)

Step 1: Calculate Applicable Amount

Lone parent or ESA allowance	£ 316.77
Enhanced Disability Premium	£ 71.01
Severe Disability Premium	£ 278.42
ESA Support	£ 163.14
Housing (mortgage)	£ 217.50
Maximum Entitlement	£ 1046.84

Figure 15: Diane's ESA if her carer claims Carer's Allowance on the left, and if she does not on the right

Case Study 3: Diane

Under Universal Credit, however, whether or not Diane's carer claims Carer's Allowance will not affect Diane's benefits. In either case, Diane's Universal Credit will include the Limited Capability for Work Related Activity (LCWRA) component, worth £328.32/month. This means that, in Diane's current scenario where her Carer receives Carer's Allowance, Diane will actually be better off under Universal Credit. Figure 16 below shows this – Diane's Universal Credit award is £95.22/month higher than her ESA under the current system.

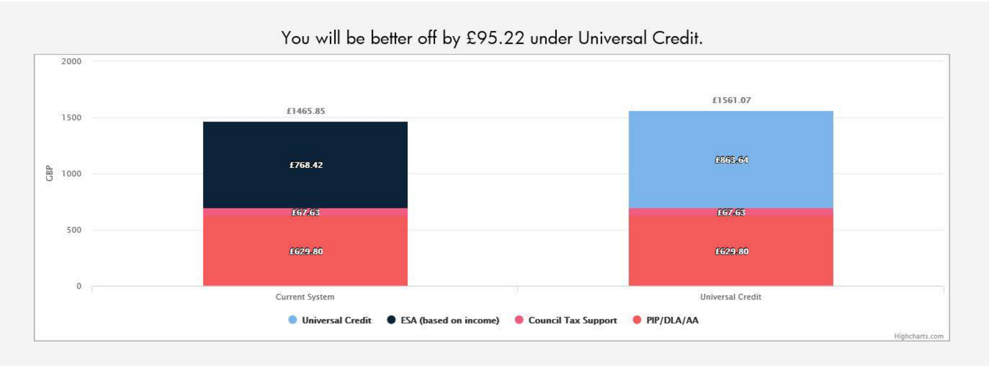


Figure 16: Diane's take-home income under the current system of benefits, compared to under Universal Credit

Although it makes no difference to Universal Credit if her carer claims Carer's Allowance or not, it does affect legacy benefits. Under legacy benefits Diane's income would be higher if her carer did not claim Carer's Allowance. The increased legacy benefits would result in an income shortfall, of £183.19/month if Diane moved to Universal Credit. This is because, under the current system of benefits, Diane would be entitled to the LCWRA plus a combination of disability premiums that is more generous than Universal Credit.

On the other hand, it should be noted that since April 2018 any mortgage support paid under both Universal Credit and the current system of benefits will take the form of a loan, to be repaid once the property is sold. Any SMI that Diane claimed before this would not have to be repaid.

Data analysis from Family Resources Survey

According the FRS data, over 2 million households in Britain currently receiving DWP benefits or tax credits (benefits replaced by Universal Credit), are neither private tenants nor social tenants. Some of these are likely to be owner occupiers claiming SMI, who like Diane would face a decision about whether to take out a loan to finance their mortgage.

The FRS data shows that 429,000 households that are eligible for Universal Credit are families in which somebody is a carer. Like Diane these households may be affected by the changes to how Carer's Allowance is considered under Universal Credit.

Key points from Diane's case:

- **Universal Credit is more generous if the carer is claiming Carer's Allowance.**
- **Universal Credit is less generous if the carer does not claim Carer's Allowance.**
- **The loss of the Severe Disability Premium for single claimants where someone does not receive Carer's Allowance results in a significant loss of income.**
- The support Diane currently receives to pay her **mortgage will become a loan from April 2018**, to be repaid with interest once she sells on her property.

Case Study 4: Ellie and Frank

Ellie and Frank are a couple with three children living in their own home in Hastings. Ellie is living with MND and claims the highest rate of PIP (both the mobility and daily living component), and is receiving £150/week in SSP from her previous employer. She has an external carer to help her who claims Carer's Allowance. Frank continues to work, and the family live in Hastings, a UC full-service area.

Under the current system of benefits, Ellie and Frank take home net earnings of £1,641.84/month, PIP of £629.80/month, SSP of £650/month, Child Benefit of £208.43/month and Child Tax Credit of £204.17/month. The fact that Frank is earning means that the family cannot claim any support with the mortgage costs, whilst the family's income is too high to qualify for any support with Council Tax.

- Couple with three children.
- Ellie receives highest PIP (mobility and daily living), plus SSP.
- External paid carer receiving Carer's Allowance.
- Frank continues to work full time, earning £24k/annum.
- Own home in Hastings.
- Savings of £14,000.

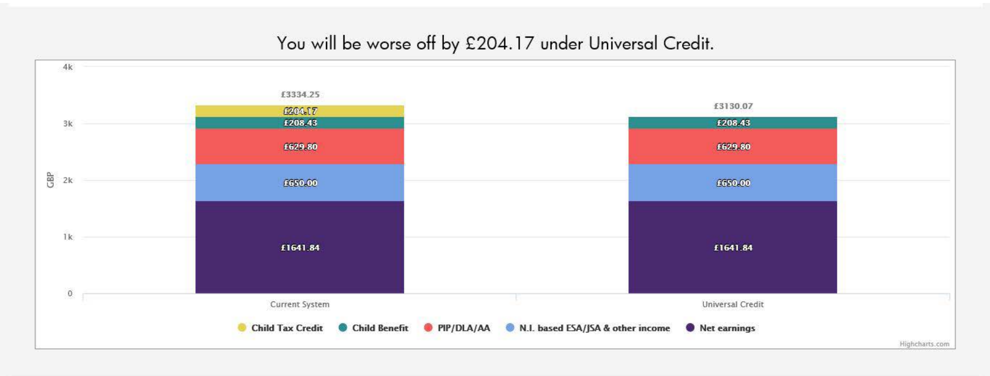
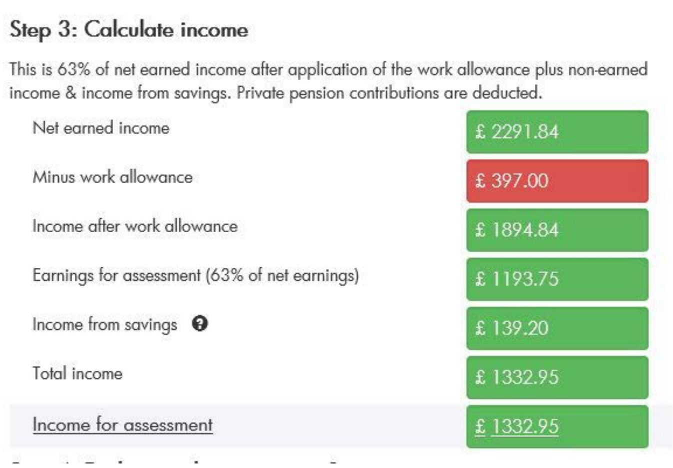


Figure 17: Ellie and Frank's take-home income under current system of benefits, versus Universal Credit

Ellie and Frank would not be eligible to receive any Universal Credit at all. As Figure 17 above shows, under Universal Credit they would face an income shortfall equivalent to the Child Tax Credit they would receive under the current system of benefits. This is explained by two main factors. Firstly, the way that earnings are taken into consideration into the calculation of Universal Credit is less favourable compared to the calculation of Child Tax Credit. Secondly, Universal Credit applies a savings limit of £6,000. This means that savings above this limit are counted as notional income in the calculation of a Universal Credit award. Figure 18, below, shows both of these points. Just £397.00/month of Frank's earnings are disregarded through a work allowance.

On top of this, Ellie and Frank's savings above £6,000 constitute a notional income of £139.20/month. This takes their total income for assessment to £1332.95/month, which would correspond to zero Universal Credit.



Step 3: Calculate income

This is 63% of net earned income after application of the work allowance plus non-earned income & income from savings. Private pension contributions are deducted.

Net earned income	£ 2291.84
Minus work allowance	£ 397.00
Income after work allowance	£ 1894.84
Earnings for assessment (63% of net earnings)	£ 1193.75
Income from savings	£ 139.20
Total income	£ 1332.95
Income for assessment	£ 1332.95

Figure 18: Calculation of Ellie and Frank's income to be considered in the calculation of Universal Credit

Case Study 4: Ellie and Frank

What if Ellie didn't receive SSP and instead decided to claim ESA?

Ellie and Frank may decide to not claim SSP. Alternatively, Ellie's employer may stop paying her SSP after a certain amount of time. In this scenario, Ellie would be eligible to receive ESA, and the impact of Universal Credit would be different. In fact, in this case, Ellie and Frank would actually be better off under Universal Credit. This is because, assuming that Ellie was in the Support group of ESA, they would be eligible to receive the Limited Capability for Work-Related Activity component within her Universal Credit award. Combined with the greater retention of earnings under Universal Credit, Frank and Ellie would therefore be eligible for £644.18/month in Universal Credit. Figure 19, below, shows how this leaves Ellie and Frank £69.57/month better off compared to the current system of benefits.

Data analysis from Family Resources Survey

There are just over 100,000 families with children in Britain with similar characteristics to Ellie and Frank, in that one member is receiving DLA/PIP and the other is working. According to the FRS data, these are households that are much more likely to experience a negative impact on household finances under Universal Credit. 68.3% of these households would see an income loss under Universal Credit, compared to an average of 40.5% for working-age households as a whole.

The FRS data also suggests that the reduction in the savings limit to £6,000 would affect just 0.9% of all working-age households eligible for Universal Credit in Britain. This corresponds to roughly 65,000 households.

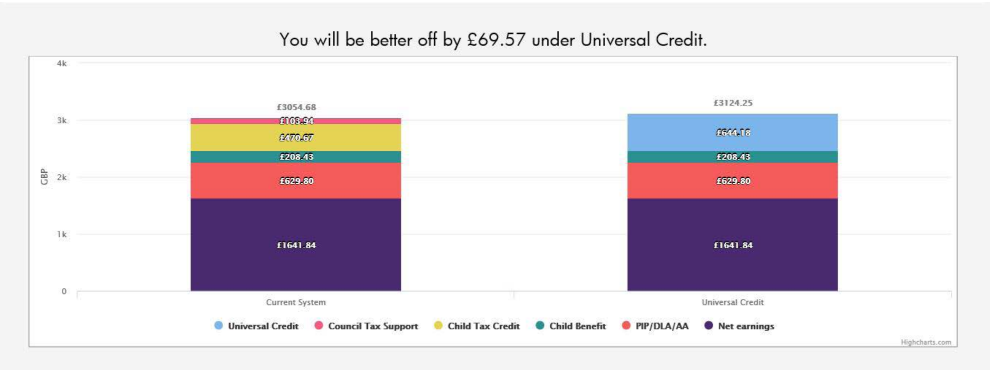


Figure 19: Ellie and Frank's take-home income in the current system of benefits, compared to Universal Credit

It should be noted that, as Ellie and Frank have three or more children, they would not be eligible to claim Universal Credit until July 2019 onwards (when managed migration is expected to begin).

Key points from Ellie and Frank's case:

- Under Universal Credit, Frank's earnings combined with the **income generated from savings above £6,000 (which were not taken into account for Tax Credits)** means they would receive zero Universal Credit.
- Frank and Ellie would not be eligible for any support to help with housing costs under either system.
- If Ellie decided to claim ESA instead of SSP, **the LCWRA component would be added to Universal Credit, and they would be better off compared to the current system of benefits**.

Appendices

Appendix 1: Overview of benefits available to people with MND

Non-means tested:

1. Disability Living Allowance
2. Personal Independence Payment
3. Attendance Allowance

Means-tested:

1. Income-based Employment and Support Allowance (ESA)
    a. Work-Related Activity Group (WRAG)
    b. Support Group
2. Income-based Job Seekers Allowance (JSA)
3. Income Support
4. Housing Benefit
5. Tax credits
6. Universal Credit (combines the above five)
7. Carer's allowance

Contributory:

1. Contributory-based Employment and Support Allowance
    a. Work-Related Activity Group (WRAG) – max 365 days
    b. Support Group – unlimited
2. Contributory-based Job Seekers Allowance

Other:

Statutory Sick Pay (SSP)

Appendix 2: Assumptions made in case studies:

- Where household lives in Private Rented Sector, we assume they have the appropriate number of bedrooms and paying rent below LHA (so that neither bedroom tax nor LHA cap is an issue)
- Assuming there are no non-dependants
- Assuming Council tax band B in every case
- Where householder is owner-occupier, we're assuming that qualifying criteria for support with mortgage payments are met
- Assuming no income from other sources, with the exception of SSP
- Assuming savings are below £16,000

Appendix 3: Income losses under Universal Credit, from FRS

Average for working-age:

uc_moreorless_now	Freq.	Percent	Cum.
Less	2,828,301	40.45	40.45
More	1,875,008	26.82	67.27
Same	2,287,974	32.73	100.00
Total	6,991,283	100.00	

Average for working-age and not receiving disability benefits:

uc_moreorless_now	Freq.	Percent	Cum.
Less	1,884,994	37.29	37.29
More	1,066,261	21.09	58.38
Same	2,103,576	41.62	100.00
Total	5,054,831	100.00	

Average for working-age and receiving both ESA and DLA/PIP:

uc_moreorless_now	Freq.	Percent	Cum.
Less	227,634	47.67	47.67
More	211,137	44.21	91.88
Same	38,753	8.12	100.00
Total	477,524	100.00	

Average for working-age and receiving both ESA and DLA/PIP:

uc_moreorless_now	Freq.	Percent	Cum.
Less	687,459	95.45	95.45
More	12,699	1.76	97.22
Same	20,048	2.78	100.00
Total	720,206	100.00	

Appendix 4: Case Study 1 (Ahmed)

Full breakdown of how Universal Credit would be calculated if Ahmed were working 10 hours per week, earning £10/hour:

Universal Credit

Step 1: Calculate any Housing Element

Gross monthly rent	£ 340.00
Deduction due to ineligible services and charges	£ 0.00
Housing Component	£ 340.00

Step 2: Calculate Maximum Universal Credit

This is made up of elements based on household circumstances

Adult	£ 317.82
Housing	£ 340.00
Maximum Universal Credit	£ 657.82

Step 3: Calculate income

This is 63% of net earned income after application of the work allowance plus non-earned income & income from savings. Private pension contributions are deducted.

Net earned income	£ 433.33
Minus work allowance	£ 192.00
Income after work allowance	£ 241.33
Earnings for assessment (63% of net earnings)	£ 152.04
Total income	£ 152.04
Income for assessment	£ 152.04

Step 4: Deduction due to income & savings

Deduct income from maximum Universal Credit

Maximum Universal Credit	£ 657.82
Minus income for assessment	£ 152.04
Universal Credit	£ 505.78

Appendix 5: Case Study 1 (Ahmed)

Full breakdown of how CTS is calculated for Ahmed once he goes onto Universal Credit:

Council Tax Support under Universal Credit

Step 1: Calculate maximum Council Tax Support

This is determined by the local Council Tax Support scheme set by the local authority

Council Tax liability	£ 86.46
Local Council Tax Support maximum	£ 77.81
Maximum Council Tax Support	£ 77.81

Step 2: Calculate Maximum Universal Credit

This is made up of elements based on household circumstances

Adult	£ 317.82
Housing	£ 340.00
Maximum Universal Credit	£ 657.82

Step 3: Calculate income

Income for Universal Credit purposes	£ 433.33
Universal Credit	£ 505.78
Income for assessment	£ 939.11

Step 4: Deduction due to income & savings

20% of any income above Maximum Universal Credit is deducted from maximum CT support

Maximum CT Support	£ 77.81
Minus 20% of income above Applicable Amount	£ 56.26
Council Tax Support	£ 21.56

Step 5: Reduction due to Local Scheme

The percentage of Council Tax Support awarded is determined by the scheme set by your local authority

AWARD	£ 21.56

Appendix 6: Case Study 2 (Beth and Carl)

Universal Credit calculation if not receiving SSP, compared to receiving SSP

Universal Credit

Step 1: Calculate any Housing Element

Gross monthly rent	£ 480.00
Deduction due to ineligible services and charges	£ 0.00
Housing Component	£ 480.00

Step 2: Calculate Maximum Universal Credit

This is made up of elements based on household circumstances

Adult	£ 395.20
Child	£ 508.75
Limited capability for work-related activity	£ 328.32
Carer	£ 156.45
Housing	£ 480.00
Maximum Universal Credit	£ 1868.72

Step 3: Calculate income

This is 63% of net earned income after application of the work allowance plus non-earned income & income from savings. Private pension contributions are deducted.

Non-earned income	£ 279.91
Minus disregarded income	£ 0.00
Non-earned income for assessment	£ 279.91
Total income	£ 279.91
Income for assessment	£ 279.91

Step 4: Deduction due to income & savings

Deduct income from maximum Universal Credit

Maximum Universal Credit	£ 1868.72
Minus income for assessment	£ 279.91
Universal Credit	£ 1588.81

Universal Credit

Step 1: Calculate any Housing Element

Gross monthly rent	£ 480.00
Deduction due to ineligible services and charges	£ 0.00
Housing Component	£ 480.00

Step 2: Calculate Maximum Universal Credit

This is made up of elements based on household circumstances

Adult	£ 395.20
Child	£ 508.75
Carer	£ 156.45
Housing	£ 480.00
Maximum Universal Credit	£ 1540.40

Step 3: Calculate income

This is 63% of net earned income after application of the work allowance plus non-earned income & income from savings. Private pension contributions are deducted.

Net earned income	£ 387.18
Minus work allowance	£ 192.00
Income after work allowance	£ 195.18
Earnings for assessment (63% of net earnings)	£ 122.97
Non-earned income	£ 279.91
Minus disregarded income	£ 0.00
Non-earned income for assessment	£ 279.91
Total income	£ 402.88
Income for assessment	£ 402.88

Step 4: Deduction due to income & savings

Deduct income from maximum Universal Credit

Maximum Universal Credit	£ 1540.40
Minus income for assessment	£ 402.88
Universal Credit	£ 1137.52

Appendix 7: A good claim journey for those living with MND

Advice received from DWP

DS 1500 obtained based on medical definition of terminal illness

Change required: medical definition of terminal illness

Third party notifies acts on behalf of the claimant and reports terminal illness

Change required: explicit consent rules

Makes online claim or calls UC helpline and notifies of terminal illness

Telephone call from specialised DWP officers offering assistance with claim and information around the Appointee process and terminal illness special rules

Visit for verification (if required)

Visit to agree Appointee (if required)

No claimant commitment interview

No Work Capability Assessment

Universal Credit award with immediate additional support through the Limited Capability of Work related Activity addition

Claim management by either claimant OR Appointee OR representative

Change required: explicit consent rules

MND Association benefits advice service

The MND Association benefits advice service provides advice by phone and e-mail in England, Wales and Northern Ireland. It also provides advice via web chat in England and Wales.

England and Wales

In partnership with Citizens Advice Cardiff and Vale, free, confidential and impartial benefits advice is available by telephone, e-mail and web chat between 9am and 5pm Monday to Friday, except on public holidays.

Call for free on **0808 801 0620** or visit **https://www.mndassociation.org/getting-support/benefits-advice/**

Northern Ireland

In partnership with Advice NI, free, confidential and impartial welfare benefits advice is available by telephone and e-mail between 9am and 5pm Monday to Friday, except on public holidays.

Call for free on **0808 802 0020** or visit **https://www.mndassociation.org/getting-support/benefits-advice/**

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