



# Six Months To Live?

Report of the All-Party Parliamentary Group for Terminal Illness  
inquiry into the legal definition of terminal illness





# Contents

<b>Foreword</b>	4
<b>Introduction</b>	6
<b>Executive summary</b>	10
<b>CHAPTER ONE</b> Claiming benefits with a terminal illness	14
<b>CHAPTER TWO</b> The current legal definition of terminal illness	18
<b>CHAPTER THREE</b> Challenges posed by the current definition for clinicians	22
<b>CHAPTER FOUR</b> Impacts of the current definition on terminally ill people	30
<b>CHAPTER FIVE</b> Concerns with the Department for Work & Pensions	44
<b>Recommendations</b>	46
<b>Appendix</b> Inquiry terms of reference and witnesses	50
<b>References</b>	51

*This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the All-Party Parliamentary Group (APPG) for Terminal Illness. This report was compiled by Marie Curie, which provides the Secretariat to the APPG for Terminal Illness.*

# Foreword

## Drew Hendry MP

Chair of the APPG for Terminal Illness



Imagine the moment a person hears from their doctor that they have a terminal illness – in that instant, nothing for them or their family will ever be the same again.

For many, their most profound wish after receiving that life-changing news is to spend the time they have left focusing on what matters; spending time with their loved ones and living as well as they can for as long as they are able. For other families, the reality of terminal illness is living with a condition that causes progressive deterioration, increasing frailty and an increasing need for care.

I have seen the impact that terminal illness has had on my constituents and on families across the country. I have also seen how little the modern reality of terminal illness is understood by politicians and government. In 2018, I set up the All-Party Parliamentary Group for Terminal Illness to raise awareness of the issues faced by people living with terminal illness and their families.

People who are living with the devastating impact of a terminal diagnosis should, at the very least, be able to expect quick and easy access to the support they need. Sadly, when it comes to the benefits system, many are not getting anything close to that.

The government's definition of terminal illness, as being when a person's death can be "reasonably expected within six months", seriously restricts access to vital financial benefits for many people. This definition is 30 years old – written in a time when many people were lucky to survive for a matter of months with conditions which, thanks to advances in treatment and care, they can now live with for longer.

In most circumstances, the fact that people are living longer with terminal illness is to be celebrated – most of us, if faced with a terminal diagnosis, would like to hope that we would be one of the people who are able to "beat the odds" and do better than our doctors expect.

However, for a person who is terminally ill, whose condition will never improve and only deteriorate until their death, but who may live for longer than six months, getting access to the benefits they need is made unnecessarily difficult by this outdated rule. Without that six-month prognosis, they are asked to go through the same benefits application as any other person.

Forcing somebody living with terminal illness to go through an intrusive face-to-face assessment process is unfair and undignified – unbelievably, this can even include asking people with months to live to attend Work Capability Assessments.

This is to say nothing of the weeks-long delays and significant financial burdens families face getting the support they need if their doctor is unable to say with confidence that they will die within six months.

Shamefully, since 2013, at least 17,000 people have died waiting for the benefits they were rightfully due.

The APPG for Terminal Illness believes that there is no evidence-based reason why the UK government cannot follow the Scottish government and allow medical professionals to certify that a person is terminally ill, entitling them to fast-track access to benefits, with no arbitrary and outdated time limit.

This will free people living with terminal illness from worrying about their finances, undergoing work assessments and filling in time-consuming forms, and allow them to focus on what really matters – living as well as they can, for as long as they are able.

I wish to pay tribute to my fellow members of the APPG for Terminal Illness for their support of this inquiry, to Marie Curie for organising the inquiry and collating this report, and to those organisations, charities, health professionals and experts who gave written and oral evidence to the APPG.

I also want to thank those members of the public – people living with terminal illnesses, their families, their friends, their carers and people who have lost someone to a terminal illness – who shared their stories with this inquiry via Marie Curie’s website.

Some of the stories of the financial hardship, stress and worry inflicted by this cruel rule, on top of coping with the devastating impact of a terminal illness, have been heart-breaking to read and must, I am sure, have been difficult to share with us. I want to assure you that your testimony has been vital to this inquiry and to our work to raise awareness of the issues faced by people living with terminal illness, and will continue to be in the months and years to come.

I hope you find this report as informative as I have.

**Drew Hendry MP**

July 2019

# Introduction

## All-Party Parliamentary Group for Terminal Illness

The All-Party Parliamentary Group for Terminal Illness (the APPG) is a cross-party group of MPs with an interest in issues around terminal illness. The APPG's purpose is to raise awareness in Parliament of terminal illness and promote links between Parliament, individuals and families affected, charities, scientists, health professionals and decision-makers.

The Group includes Members of Parliament from across the political spectrum who are keen to discuss, improve and share knowledge of terminal illness and end of life care.

The APPG meets several times a year to discuss topics surrounding terminal illness with individuals and organisations involved or interested in this area.

APPG for Terminal Illness membership:

- **Drew Hendry MP** – Chair
- **Jim Shannon MP** – Vice-Chair
- **Christine Jardine MP** – Vice-Chair
- **Carol Monaghan MP** – Vice-Chair
- **Hugh Gaffney MP** – Vice-Chair
- **Tom Tugendhat MP** – Officer
- **Sir John Hayes MP** – Officer
- **Marion Fellows MP** – Officer

## Secretariat

Marie Curie supports the work of the APPG for Terminal Illness through providing its secretariat.

Marie Curie is the UK's leading charity for people affected by terminal illness. It delivers palliative and end of life care directly to people across the UK, both in their own homes and in its nine hospices. It runs an information and support service, which helped over 50,000 people last year. It is also the largest charitable funder of palliative and end of life care research in the UK and a leading voice in the UK calling for improved access to and quality of palliative and end of life care.



Care and support  
through terminal illness

Charity reg no. 207994 (England & Wales),  
SC038731 (Scotland)

## About this inquiry

The current legal definition of terminal illness in UK law states that someone must have six months or less to live to claim benefits under the Special Rules for Terminal Illness, entitling them to fast-track access and automatically receiving the highest rate of payment. The relevant benefits are Universal Credit, Employment and Support Allowance, Personal Independence Payment and Attendance Allowance.

This definition of terminal illness was written into legislation at Westminster in 1990 and, since then, the nature of dying and prognostication has changed. Due to advances in treatment, we expect people to be terminally ill for longer. In addition, while many forms of cancer have a relatively reliable prognostication, other conditions such as neurological disorders and organ failure are much more difficult for doctors to prognosticate.

As many people with a terminal diagnosis do not fulfil the six-month life expectancy criteria, they instead have to go through the standard process in accessing benefits. This means having to wait longer to get the benefits they are entitled to, filling in long and complicated forms and also going to work assessments.

The APPG agreed to examine the impact of the six-month rule on terminally ill people's ability to access benefits in 2019.

Its objectives were:

- Further build evidence and understanding of the opportunities and challenges of the six-month rule
- Hear from a wide range of experts, policy-makers, healthcare professionals and people who have dealt with the six-month rule
- Provide recommendations to policy-makers on ways to improve the legal definition and guidance to healthcare professionals.

## Mark's story

**Mark Hughes, who has terminal bone cancer, explains the challenges he faced trying to claim benefits through the DWP. Mark has been living with cancer for 19 years – he worked as a long-distance truck driver until 2011, when he was given the news that his cancer was terminal and he could no longer work.**

“I told the DWP I was unable to continue working and a few days later I got the first set of forms to fill in. I had numerous letters from them over months with the same questions being asked over and over again. Sometimes, forms were sent by mistake – I was having to deal with all of this while still dealing with the news that I was terminally ill.

“Eventually, Macmillan helped us, and I was given full benefits. Then, after I got my pension of £16,000 through, the DWP just stopped half my benefits. They sent somebody from the fraud department.

*“My benefits were stopped because my cancer didn't give me the right number of points to get any benefit... I was told that they did not contact doctors or hospitals for medical details.”*

Even once it had been proven I wasn't trying to abuse the system, they never apologised.”

Mark explains what happened after he was visited by a DWP assessor.

“Someone then came for a home visit and asked me questions like if I was able to cook, to eat, to read – I feel like this is entrapment because, if you're honest, you lose out. I was told to fill in the form as if it was my worst day.

“After the home visit, my benefits were stopped because my cancer didn't give me the right number of points to get any benefit. The people who came to the house weren't medically trained and when I appealed, I asked them to contact my GP, which they said they wouldn't do. I was told that they did not contact doctors or hospitals for medical details.

“When you look at me, I still look fine and not visibly unwell, so, in their eyes, there was nothing wrong with me. The system is set up to catch you out – the more honest you are, the more you are penalised.

“On appeal, I got enough points to receive part of the benefits, but not the full amount. They also gave me a letter telling me I wouldn't be contacted until 2025.

“Then, in November 2018, I got the same assessment form again that had led to the



Marie Curie

home visit. I called the DWP and they said, 'You don't have to fill in the form', but, after what happened before, my wife and I spent two days filling it in. It was the same form sent with the letter saying they wouldn't contact me, but now it said I only had until 31 January to complete the form."

The DWP then stopped sending Mark's Employment and Support Allowance in November 2018.

"I contacted Jobcentre Plus, who couldn't give me a reason why the payments were

stopped. Then, a few days later, I received a letter saying I was entitled to benefits.

"The DWP also asked me how I was spending my money and my savings and asked me if I was using it in a 'responsible way'.

"Since 2014, only one person at the DWP has ever tried to help me. Every time I get a letter from them, I'm worried."

## Executive summary

*“I have friends and family who are either living with terminal illness or have died – it’s dreadful to see them devastated by these illnesses, but even worse to see them wasting precious moments worrying about money.”*

**F**ast-track access to benefits is a lifeline for people living with a terminal illness.

With support from a clinician by way of a DS1500 form giving details of a person’s condition, benefit applications and decisions are fast-tracked, and inappropriate assessments are avoided. This allows terminally ill people and their families quick access to the financial support they need and lets them focus on what matters to them during the time they have left.

However, the law only recognises that a person is terminally ill if their clinician believes that their death “can be reasonably expected within six months”.

**17,000**  
people died  
between April  
2013 and April  
2018 while  
waiting for a  
decision on  
their PIP claim

Terminally ill people whose doctors cannot make that prognosis must face the standard benefits application process – waiting longer before decisions and payments are made and being subjected to capability assessments and work search requirements.

This “six-month rule” was introduced into law in 1990 to exempt terminally ill people from the six-month qualifying period for the Attendance Allowance – it was not initially intended to be a wider definition of terminal illness and the timescale has no clinical meaning in most cases.

However, the definition has subsequently been extended to new benefits and today also applies to Universal Credit, Personal Independence Payments and Employment and Support Allowance, as well as the Attendance Allowance.

In 1990, many terminally ill people were unlikely to survive for six months after receiving a terminal diagnosis – today, advances in treatment and diagnosis mean that many more people are living with terminal illness for longer, more people are surviving cancer and many conditions that were considered terminal when the law was introduced are no longer considered to be terminal.

The six-month rule also wrongly assumes that life expectancy can always be accurately predicted.

It is very challenging for clinicians to estimate how long someone has left to live – studies have shown that the accuracy of such predictions ranges from 78% to just 23% – and, in the case of rarer and less well-understood conditions such as Motor Neurone Disease, it can be impossible.

Clinicians’ interpretations of the law also vary significantly, and many believe they will be held accountable if their prediction turns out to be wrong.

It is therefore unsurprising that nearly a third of GPs say they have never signed a DS1500 form to support a Special Rules benefits application for a condition other than cancer.

Under the current law, patients' access depends on the attitude of their doctor, and many terminally ill people are excluded if they are likely to be living with terminal illness for more than six months or the prognosis of their condition is hard to predict.

Terminally ill people who claim via the normal benefits rules face a process that is extremely burdensome and time-consuming for somebody living with the emotional and physical impact of a terminal diagnosis.

Forced to go through assessments and inappropriate work-focused interviews, many are turned down or awarded benefits at the lower rate.

They must then wait weeks or even months before receiving their first payment, potentially with no other source of financial support if their condition means they cannot work, often leading to significant stress and financial difficulties.

Tragically, between April 2013 and April 2018, 17,000 people in Great Britain died waiting for a decision on their PIP claim – an average of 10 people every day.

Even under the Special Rules, people who live with a terminal condition for longer than three years must re-apply for benefits – obtaining a new DS1500 from

their doctor and facing the burdensome application process again.

The assumption that people with terminal illnesses will need support only for a matter of months until they die is outdated and does not reflect the modern reality of many terminal conditions, where people can live and need ongoing support for several years with conditions that cause progressive debility over time.

Even where a clinician has signed a DS1500, in some cases the Department for Work & Pensions challenges their judgment and rejects the evidence they provide.

This can mean that non-specialist assessors are overruling the judgment of clinicians who have first-hand knowledge of a patient's condition and prognosis.

The current legal definition of terminal illness, with its "six-month rule", is unfit for purpose – it is outdated, arbitrary and not based on clinical reality.

It is ironic that this measure, originally designed to help terminally ill people avoid a long wait to qualify for benefits has, in practice, become a barrier to access for many people with terminal conditions.

Clinicians, social and palliative care workers and medical experts all recommended to the APPG that it should be changed.

In Scotland, the Social Security (Scotland) Act 2018 has amended the law to recognise a person as terminally ill where it is the clinical judgment of a medical practitioner that they have a progressive

disease that can be reasonably expected to cause their death, without an arbitrary timescale.

The Scottish government is consulting on new guidance for clinicians on relevant clinical factors to consider and information to support them making this clinical judgment process; it is not expected that every person with a progressive condition that may cause their death will automatically be entitled to access the Special Rules as soon as this diagnosis is made.

This approach better reflects the clinical reality of terminal illness and advances in prognostication over the last three decades – however, it will create a “two-tier” benefits system in Scotland and inconsistency across the UK as only Personal Independence Payments and Attendance Allowance are devolved.

The UK government must take steps to make the definition of terminal illness in the benefits system fit for the 21st century and equalise the law across the UK.

The APPG recommends:

- amending the definition of terminal illness in UK law so that a person is regarded as having a terminal illness if it is the clinical judgment of a registered medical practitioner or clinical nurse specialist that they have a progressive disease that can reasonably be expected to cause the individual’s death
- adopting a light-touch review of benefit awards under the Special Rules for Terminal Illness only after 10 years, with the DWP only contacting the claimant’s

GP to confirm that their diagnosis and prognosis remain the same

- ending the practice of non-specialist DWP assessors challenging and rejecting the medical evidence provided by clinicians in a DS1500 form to support a benefit claim under the Special Rules.

In July 2018, Madeleine Moon MP presented a Ten-Minute Rule Bill, the Access to Welfare (Terminal Illness Definition) Bill 2017-19.

The Bill proposes to replace the requirement of “reasonable expectation of death within six months” with a clinical judgment made by an appropriate health professional.

This Bill would address the APPG’s first recommendation and we call on all MPs to support the Bill.



## CHAPTER ONE

# Claiming benefits with a terminal illness

*“Eligibility for a DS1500 is a lifeline for the terminally ill people who qualify.”*

### Citizens Advice

**T**erminally ill people who are expected to have less than six months to live are entitled to fast-track access to many welfare benefits at the highest level of payment – including Universal Credit, the Personal Independence Payment, Employment and Support Allowance and Attendance Allowance (referred to in this report as “the Relevant Benefits”).

This fast-track access means that decisions on benefits are made much more quickly for people living with a terminal illness and, in the case of most benefits (but not Universal Credit), they are paid more quickly.

This is of the utmost importance to people who have received a terminal diagnosis; avoiding stressful and time-consuming tests and assessments allows them to focus on what matters to them in the time they have left – spending time with their family, friends and loved ones, and making memories – and not worry about finances or spending precious time filling in long, complicated forms.

### Special rules for Terminal Illness

Benefits access under the Special Rules for Terminal Illness process (the “Special Rules”) recognises that satisfying many of the conditions for eligibility for welfare benefits as part of a standard application (the “Normal Rules”), such as assessments

of their capability for work, is not appropriate for terminally ill people.

It also recognises that quick decisions are of particular importance to people with limited time to live.

To support a claim for one of the Relevant Benefits under the Special Rules, a clinician – such as a GP, hospital consultant or specialist nurse – will complete a DS1500 form, giving details of the claimant’s condition.

The DS1500 is not part of the application for the Relevant Benefits, but it is used to provide medical facts about the patient’s condition and prognosis in support of that claim.

The difference that a claim under the Special Rules makes varies depending on the benefit being applied for, but applications and decisions are fast-tracked compared to claims under the Normal Rules and claimants typically qualify for a higher rate of benefits without the need for a medical assessment.

Witnesses to this inquiry agreed that for those who can access it, the Special Rules process usually works well – Citizens Advice calls the Special Rules “a lifeline” for those who can access them.

How the Special Rules apply to each of the Relevant Benefits is outlined in the box on the next page.

## Personal Independence Payment (PIP)

Claimants don't have to wait the three-month qualifying period to get PIP and automatically qualify for the enhanced rate of the PIP daily living component. They will not have to fill in the "How your disability affects you" form.

Claimants won't automatically qualify for the mobility component, but a decision about it may be quicker. Claimants will be asked questions about their mobility at the start of their claim – if they do qualify for the mobility component, they will not have to wait the three-month qualifying period for it.

## Attendance Allowance

Claimants don't have to wait the six-month qualifying period to get Attendance Allowance and automatically qualify for the higher rate of Attendance Allowance.

## Employment and Support Allowance (ESA)

Claims for ESA can be fast-tracked, and claimants will also be put in the "support group" of claimants and will not be reassessed after 12 months. They will be paid a higher rate of ESA and will not have to meet work-related responsibilities to keep getting the benefit in full.

Most people don't get any money for the first seven days of their claim. But claimants under the Special Rules will be paid for these days.

## Universal Credit

Universal Credit claimants must wait around six weeks for their first payment. There is no fast-track for terminally ill people.

Special Rules 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 also be paid at a higher rate, as a "work capability amount" will be included in the award.

## The Normal Rules

For those patients who are unable to satisfy the current legal definition of terminal illness, accessing the benefits they need is significantly more complex – they must make their claims under the Normal Rules.

Without a DS1500 form completed by a clinician, claimants for each of the Relevant Benefits must complete additional forms and provide additional supporting documents detailing their condition. Applications under the Normal Rules also require the claimant to attend either a face-to-face consultation with a DWP assessor or a mandatory Work Capability Assessment interview, depending on the benefit.

Eligibility for these benefits under the Normal Rules is assessed and determined based on capability rather than on a person's condition – assessments consider the degree of difficulty that claimants have with everyday tasks, such as preparing meals or walking unaided for short distances, or the level of support needed on a day-to-day basis. The Personal Independence Payment uses a points-based test to determine eligibility for and the rate of benefits awarded.

If an application under the Normal Rules is successful, claimants must then wait for longer before their benefits are awarded and paid, compared to those claiming under the Special Rules, as outlined on the previous page.

Additional qualifying requirements apply to PIP and Attendance Allowance applications, which mean the claimant must have needed support for a minimum of three months (six months for Attendance Allowance) and expect to need it for at least another nine months.

Employment and Support Allowance benefits are automatically paid at a lower rate for a 13-week assessment period at the start of a claim – and further delays after this period are common.



## CHAPTER TWO

# The current legal definition of terminal illness

*“At the point they begin to need financial support, brain tumour patients rarely fulfil the six-month life expectancy criteria.”*

### Brain Tumour Research

The law only recognises that a person is terminally ill where they are “suffering from a progressive disease and the person’s death in consequence of that disease can reasonably be expected within six months”.<sup>1</sup>

According to the DWP’s guidance for clinicians on interpreting the law, this does not mean that a person is more likely than not to die within the next six months, but simply that their death within six months would not be unexpected.

This is the basis on which clinicians must judge whether they can complete a DS1500 form for a claimant to access the Relevant Benefits via the Special Rules.

### Origin of the definition

This definition was introduced into the benefits system in the Social Security Act 1990<sup>2</sup> – as part of an amendment to Social Security Act 1975 to exempt the terminally ill from the requirement for a person to have been ill for a minimum six-month period to qualify for the Attendance Allowance.

A similar amendment had been put down during House of Lords debates around the Social Security Act 1989, but was withdrawn after undertakings from ministers to consider the issue further<sup>3</sup>, resulting in its inclusion in the 1990 Act the following year.

The definition introduced by the Social Security Act 1990 was that:

*a person is “terminally ill” at any time if at that time he suffers from a progressive disease and his death in consequence of that disease can reasonably be expected within six months.*

At the time, politicians were concerned that the six-month qualifying period requirement under the Attendance Allowance was unfairly penalising terminally ill people at a time when many people with terminal illnesses died within six months of receiving a terminal diagnosis<sup>4</sup> – and so before they were eligible to claim the Attendance Allowance.

The Social Security Advisory Committee had similarly recommended to the government in 1988 that it should waive the six-month qualifying period for the Attendance Allowance for patients whose doctors had certified that they were terminally ill<sup>5</sup>.

A particular concern among lawmakers at the time was for people with terminal cancer or HIV/AIDS diagnoses. When this debate was taking place in 1990, people with these conditions could die very quickly after receiving a terminal diagnosis and so be unable to benefit from the Attendance Allowance before the law was changed<sup>6</sup>.

The definition of terminal illness introduced in the Social Security Act 1990 should therefore be understood in this context – exempting terminally ill people from a specific requirement for eligibility for a specific benefit that was unfairly penalising them – and not as being a wider definition of “terminal illness” reflective of clinical or prognostic factors.

Indeed, at Second Reading, the then-Secretary of State described the intent of the relevant clause as “abolish[ing] the Attendance Allowance six-month qualifying period in respect of terminally ill people”<sup>7</sup>, not as introducing a wider definition of terminal illness.

However, the form of words used in that clause has since been applied by successive governments in further legislation for other benefits terminally ill people can claim. It was first extended by the Social Security and Benefits Act 1992 when the definition was used in relation to claims by terminally ill people for the Disability Living Allowance, and then through subsequent legislation up to and including the Welfare Reform Act 2012.

It has, therefore, become the default definition of terminal illness used in UK law.

Today, the six-month definition of terminal illness applies, unchanged since its introduction in 1990, to each of the Relevant Benefits – the definition also applies elsewhere, for example in the rules for accessing a terminal illness lump sum in pensions law.

Advances in diagnosis and treatment over the last 30 years mean that the nature of dying and prognostication have changed significantly since the six-month definition was introduced. Indeed, while HIV, which was of particular concern to lawmakers when introducing this definition, was considered a terminal illness in 1990, today if a patient has access to the right care and medication, they have a normal life expectancy. Similarly, today more people are surviving cancer than ever before.

Unlike in 1990, when many people died far sooner than six months after a terminal diagnosis, today many more people instead live with terminal illness for longer and die from conditions with significantly less predictable prognoses than, for example, most of the common forms of cancer.

## Recent developments

The DWP has recently updated its guidance on completing DS1500 forms, to advise clinicians that a terminal illness is one where “you would not be surprised if your patient were to die within six months”<sup>8</sup>.

This change softens the language of a “reasonable expectation” of a patient’s death within six months. However, the “reasonable expectation” persists in law and, nevertheless, this change to the guidance does nothing to address the key drawback of the current definition – the arbitrary six-month timescale it uses to define terminal illness.

**The legal definition of terminal illness has not changed since 1990**

In evidence to this inquiry, the Motor Neurone Disease Association told us that this will “limit the impact of the revision and allow ongoing uncertainty”.

An alternative approach has been taken in Scotland, where the Social Security (Scotland) Act 2018 amends the definition of terminal illness for access to the Personal Independence Payment and Attendance Allowance under the Special Rules, from April 2020, to recognise a person as terminally ill where:

*it is the clinical judgment of a registered medical practitioner that the individual has a progressive disease that can reasonably be expected to cause the individual's death.*<sup>9</sup>

This approach reflects a growing understanding of the challenges in making an accurate prognosis for people with terminal conditions and comorbidities. The change will allow clinicians to certify a patient is terminally ill in support of their claim for Personal Independence Payments or Attendance Allowance based only on their clinical judgment as to the patient's needs, not an arbitrary six-month timescale.

A June 2018 review of the Personal Independence Payment process in Northern Ireland also concluded that the six-month criteria should be removed and replaced with one based on clinical judgment<sup>10</sup> as in the Scottish approach.

As noted by the Law Centre (NI), this approach has cross-party support in

Northern Ireland, with six parties (DUP, SF, SDLP, UUP, Alliance, Greens) writing a joint letter to the Department for the Communities in support of the change<sup>11</sup>, although the review's recommendation has not yet been acted upon by the Department due to the current lack of a Northern Ireland Executive government.

The Scottish government has consulted with clinicians and other stakeholders on new guidance for clinicians on how to exercise their clinical judgment to determine whether a patient is terminally ill for the purposes of accessing benefits, including relevant clinical factors to consider and information to support the clinical judgment process.

As Mark Hazelwood of the Scottish Partnership for Palliative Care explained to the APPG, the expected approach in Scotland is that this guidance will include indicators – such as whether a patient's condition is sufficiently advanced or progressive, or whether it is not amenable to further curative treatment – to help clinicians identify and characterise people who are likely to be eligible, supported by clinical indicators for some specific conditions.

Clinicians would then be asked to make a clinical judgment as to whether their patient fits that model or not – it is not expected that every person with a progressive condition that may cause their death will automatically be entitled to access the Special Rules as soon as this diagnosis is made.

The forthcoming legislative change in Scotland will, however, create a two-tier system in Scotland upon its introduction – as Universal Credit and Employment and Support Allowance are reserved benefits and will remain subject to the six-month rule. It will also lead to inconsistency across the four nations of the UK.

Parkinson's UK outlined how one example of this inconsistent, two-tier system will affect claimants; while the Scottish government has confirmed that a DWP DS1500 will be accepted as proof of eligibility for devolved benefits under the Special Rules, there is no suggestion that a completed Scottish form will be accepted by the DWP as proof of eligibility for reserved benefits.

In England, in July 2018 Madeleine Moon MP presented a Ten-Minute Rule Bill titled Access to Welfare (Terminal Illness Definition) Bill 2017-19.

The Bill proposes to replace the requirement of “reasonable expectation of death within six months” with a clinical judgment made by an appropriate health professional. In effect, the Bill would replicate the change made in Scotland.

## CHAPTER THREE

# Challenges posed by the current definition for clinicians

*“The current legal definition of being terminally ill as having six months left to live is definitely not fit for purpose.”*

**MND Scotland**

No clinical definition of terminal illness or end of life uses or has ever used the six-month timescale used in the current benefits law; this is unsurprising, as the definition stems from the rules around claiming Attendance Allowance and is not based on clinical considerations.

The Royal College of Physicians told us that “the legal definition of terminally ill is not in keeping with the definition of ‘end of life’”, while Hospice UK agrees that it “lacks clinical relevance”.

The Royal College of General Practitioners surveyed 150 end of life care advisers (GPs) for its submission to this inquiry; 84% agreed that the six-month definition is not fit for purpose.

The nature of dying and prognostication has also developed significantly since 1990 – new treatments and improvements in palliative and end-of-life care mean that many more people are living with a terminal illness for longer, and six months is a very short timescale compared to the progression of many terminal conditions.

The General Medical Council’s definition of the end of life says that patients are “approaching the end of life” when they are likely to die within 12 months<sup>12</sup>; other definitions define the end of life as anything between 72 hours to a year or longer before death, depending on the specific purpose of that definition – none, however, uses a timeframe of six months. The timeframe used in benefits legislation is, therefore, wholly unrelated to how the medical profession thinks and talks about the end of life.

According to the Motor Neurone Disease Association, the six-month timescale also “wrongly assumes that life expectancy can be accurately estimated for people living with terminal illness”, and in a letter to The Times in April 2018, 50 medical professionals agreed that “six months life expectancy has no clinical meaning in most terminal illnesses”.<sup>13</sup>

## Challenges identifying end of life for patients with non-cancer conditions

*“Identification of people who are at the end of life is very poor – it is very difficult for general clinicians to identify somebody at the end of life.”*

**Dr Sarah Cox, RCP**

Dr Clare Gardiner, Senior Research Fellow at the School of Nursing & Midwifery, University of Sheffield, explained that “for patients with cancer, it is relatively easy to prognosticate and predict when someone is within six months of death”. However, many other terminal illnesses have a far less predictable prognostication – which can mean it is particularly challenging for clinicians to reliably estimate when patients with these conditions are entering the end of life.

According to the Scottish Partnership for Palliative Care, the current law “relies on a degree of prognostic certainty, which is often difficult to attain”.

While a third of patients with Motor Neurone Disease (MND), for example, will die within a year of diagnosis and half within two years<sup>14</sup>, it is very difficult for clinicians to accurately predict which MND patients are likely to die sooner than others – the Motor Neurone Disease Association told us that “with our current level of understanding of MND, it is not possible to give a precise prognosis of life expectancy in individual cases”.

Similarly, as explained by Parkinson’s UK, people with Parkinson’s disease typically follow a prolonged trajectory of increasing frailty rather than the more sudden and rapid decline seen in the end stages of cancer, and “clinicians are very poor at identifying that people with Parkinson’s are reaching the end of life”.

This is also true for other non-cancer conditions – a recent review of prognosis in chronic obstructive pulmonary disorder (COPD) found that current evidence or prognostic tools do not allow clinicians to reliably predict which patients with COPD are approaching end of life<sup>15</sup>.

The Scottish Partnership for Palliative Care told us that the degree of uncertainty involved in conditions such as heart failure, COPD and frailty often mean that people are not identified by professionals as approaching the end of life – with or without a timescale – and people with these conditions are less likely to consider that they may be approaching the end of life, compared with those living with cancer.

Indeed, a study of GP practices showed that, even at death, only 40% of non-cancer patients had been formally identified as being near the end of life for the purposes of providing palliative care<sup>16</sup>. In the same study, while cancer patients were more likely to have been identified as at the end of life, one in four still had not been identified by the time of their death.

Similarly, the National Association of Welfare Rights Advisers shared experience of clinicians not recognising patients’ conditions as terminal – and so refusing to sign a DS1500 – despite having a terminal



**Only 40%**  
of non-cancer  
patients are  
formally  
identified as  
being near  
the end of life  
at the time  
they die

prognosis, because the patient was still receiving treatment and the clinician did not recognise them as approaching the end of life for this reason.

As a result, conversations relating to end of life issues, including access to benefits, are less likely to occur with those patients whose clinicians have not made the identification that they are nearing the end of their lives.

The Royal College of General Practitioners explained that, as most patients are not well informed as to what support is available and rely on being signposted by their doctor to the benefits they are entitled to, if clinicians are not identifying patients as approaching the end of life, many people will miss out on being able to claim.

Requiring a strict six-month prognosis can, therefore, exclude many people living with less well-understood, or less certain, conditions from accessing benefits quickly.

## Challenges making an accurate prognosis

*“It is incredibly difficult to predict with any degree of accuracy how long someone has left to live.”*

**Dr Clare Gardiner,  
University of Sheffield**

Even where clinicians do correctly recognise that patients are entering the end of life stage of a terminal illness – which the General Medical Council regards as being 12 months or less, not six months

– studies have shown that the reliability of healthcare professionals’ estimates of how long terminally ill people have left to live varies significantly.

Researchers at the Marie Curie Palliative Care Research Department at University College London have found that clinicians are frequently inaccurate when predicting how long those living with terminal illnesses will survive.

The researchers assessed the accuracy of clinicians’ predictions about how long terminally ill patients would live across a series of studies consisting of over 4,000 patients. They found that the accuracy of these predictions ranged from 78% to just 23%<sup>17</sup>.

According to Professor Patrick Stone of the Marie Curie Palliative Care Research Department, clinicians’ predictions are less likely to be accurate over a longer timescale – they are more likely to make an accurate estimate when predicting a patient will survive for weeks than for months or years.

Due to the difficulty in making accurate predictions, many of the prognostic tools designed to help doctors identify patients who are approaching the end of life and may benefit from palliative care, such as the Supportive & Palliative Care Indicators Tool (SPICT), do not give a prognostic timeframe; they are designed only to identify patients in need of such care.

Professor Stone explained that these tools are often “as good but no better” than clinicians’ own intuition in predicting life expectancy, and that studies have

shown that clinicians are “systematically overoptimistic” in their predictions of life expectancy. In one such study, clinicians’ predictions were shown to be over-optimistic by a factor of five<sup>18</sup>.

Subsequent research has also shown that the reliability of less-specified predictions of life expectancy also varies considerably.

Reviewing a further series of studies, researchers found that the accuracy of the “Surprise Question” (“Would you be surprised if this patient died within the next x months?”) approach to identifying people nearing the end saw a similar level of inaccurate predictions – with an accuracy level of 74.8%<sup>19</sup>.

As evidence from the Royal College of Physicians explained, the Surprise Question creates both false positive outcomes – those patients who survive longer than predicted – but also, crucially, false negative outcomes, where patients die within a given timeframe after a clinician has said they would be surprised if death occurred within that timeframe. Professor Stone advised that the Surprise Question can be accurate less than half of the time and that it is “better at identifying those patients who are going to live”, with less effectiveness as a “screening question” for identifying patients likely to die.

This is the same approach that the Department for Work & Pensions (DWP) advises clinicians to consider in its updated DS1500 guidance (although the statutory definition remains unchanged) – that the practitioner “would not be surprised if [their] patient was to die within six months”<sup>20</sup> – to determine life expectancy.

This approach is therefore likely to lead to an inaccurate prognosis in at least one case in every four and potentially more, with studies again showing that clinicians’ estimates using the Surprise Question are less accurate for non-cancer patients.

Even when patients are much closer to death, clinicians still struggle to make reliably accurate predictions. Research at the Marie Curie Palliative Care Research Department has shown that even where clinicians are very confident that a patient will die within the next 72 hours, these estimates are only correct 75% of the time<sup>21</sup>.

The conclusions from these studies indicate that it is important for the law to recognise the uncertainty involved in even the most confident of predictions of life expectancy – and underline the significant challenge clinicians face in making an accurate prognosis, not only over a timescale of months, but even when death is imminent.

There is significant difficulty for clinicians in making an accurate prediction of life expectancy to a specific timescale. For example, in a survey conducted by the Motor Neurone Disease Association, only 7% of neurologists and 5% of GPs agreed that the condition of a person living with MND “always makes it clear whether they should sign the DS1500” for a benefit claim<sup>22</sup>.

St Christopher’s Hospice told the APPG that “it is increasingly incongruent to define terminal illness with a time limit”, and noted that “clinical staff are reporting that trying to ascertain prognosis is taking up more and more of their time”.

## Other challenges for clinicians

*“Doctors can be fearful about giving a person a prognosis of less than six months, so people aren’t identified for fast-track support.”*

### Dignity in Dying

In addition to the challenge for clinicians of accurately predicting how long somebody living with a terminal condition has left to live, clinicians’ interpretation of the six-month definition used in law also varies significantly.

The legal test that death can be reasonably expected within six months is a subjective one and different clinicians will interpret the “reasonableness test” differently.

The Motor Neurone Disease Association notes that there is “variation in how the Special Rules criteria are interpreted”, and therefore in doctors’ willingness to submit a DS1500 for their patients.

There are many reasons that clinicians may be reluctant or unwilling to issue a DS1500 form in support of a patient’s benefits claim.

Firstly, the rigidity of specifying a six-month life expectancy is difficult to align with the objectives of treatment for many patients receiving palliative care, which are focused on giving patients the best opportunity to live with a terminal illness for as long as possible.

As the Royal College of General Practitioners told the APPG, doctors may be concerned that a patient’s state of mind will be negatively impacted upon hearing their life expectancy may only be six months – even if this is only a “reasonable expectation”. It may rob them of the hope of a better outcome and even impact the doctor/patient relationship in some cases.

Evidence to this inquiry also identified a “generalised fear” among medical professionals of “making a mistake and being pulled up on it” if a patient subsequently lives longer than the six months specified in the law, after they have signed a DS1500 for that patient.

Despite the DWP’s insistence that it expects clinicians to be “flexible” in how they make this judgment, many clinicians continue to interpret the law as a rigid “six-month rule” and will not sign a DS1500 for a patient in cases where they believe – or hope – that there is a chance of them surviving for more than six months.

Tenovus Cancer Care, for example, identified a “common misconception” among clinicians about the definition, noting that “some consultants are still willing to complete the DS1500 form, but some are very stringent”.

The clinicians who gave evidence to the APPG agreed that the profession is unsure about how the definition should be applied, with many doctors simply not having read the DWP guidance that explains how it expects clinicians to interpret the “reasonable expectation” of death within six months.

Notably, this explanation is not provided on the DS1500 form itself, which is all that many professionals will refer to when being asked to sign one on behalf of a patient.

Indeed, the DWP's assumption that clinicians will be "flexible" goes against a clinical culture identified by several clinicians where "professionals feel they need to be 100% accurate in their predictions of life expectancy".

According to the National Association of Welfare Rights Advisers, some clinicians do not understand how the DWP looks at DS1500 forms or have a limited understanding of the impact on patients of going through a Normal Rules claim as opposed to a Special Rules claim, and therefore under-appreciate how important a DS1500 is in getting their patients the fast-track access to benefits they need.

Finally, patients may be aware that they are terminally ill, but have requested clinicians not to tell them of their expected prognosis. While the law allows third parties to claim on behalf of people living with a terminal illness in these circumstances, as Advice Northern Ireland pointed out in its evidence, patients may miss out on a Special Rules claim they are otherwise eligible to make unless they are dealing with a specialist adviser who is aware of and able to navigate this process.

These differences in interpretation of the law and the six-month definition lead to situations where, as the Motor Neurone Disease Association told this inquiry, "claimants' access to the Special Rules

process depends to a large extent on the attitude and interpretation of individual clinicians, leading to variation and inequity of access" – with patients living with conditions that have a less reliable progression than cancer being especially disadvantaged.

Notably, nearly a third (31%) of GPs say that they have never signed a DS1500 form for a condition other than cancer<sup>23</sup>.

It is, therefore, of little surprise that data from the Department for Work & Pensions shows that only 44% of Personal Independence Payment claimants with MND claimed under the Special Rules<sup>24</sup> – despite MND being terminal in all cases. Data from Northern Ireland, similarly, shows that 85% of people receiving PIP through the Special Rules have terminal cancer<sup>25</sup>, despite cancer only accounting for 28% of all deaths in Northern Ireland<sup>26</sup>.



**Nearly  
one  
third**  
of GPs have  
never signed  
a DS1500 for  
a non-cancer  
patient

## Martine's story

**Martine Adams, 28, from Barry in Wales, was diagnosed in January 2019 with a diffuse leptomeningeal glioneuronal tumour, a rare cancer of the central nervous system. She talks about her experience. Martine is married to Scott, who had acute myeloid leukaemia from the age of two and was only discharged last year.**

"I was diagnosed this year, but I started to become unwell in the August (2018). I think we had Scott's [discharge] letter through in maybe July, and then in August I started feeling unwell. I was just crippled over in pain. I was like the Hunchback of Notre Dame. I couldn't stand up. I went to the doctor and they treated me for sciatica.

"I kept going back to the doctor, maybe every week – if not sometimes twice – and my doctor was giving me tramadol and all these meds, but then I started to get these headaches, so he kept sending me in to assessment units."

*"I remember ringing PIP, pressing the number for terminal, and the lady on the phone said, 'Hello, have you got six months or less to live?' I said no, and she said, 'Oh, well that's what this is for.'"*

After months of assessments and tests, doctors found a tumour they believed to be benign and Martine opted to have it removed.

"I had my op on 29 November to remove the tumour at the base, and a biopsy was taken. They didn't remove it all, but they removed what they could. The rest is trapped around very important nerve endings.

"Five weeks later, on 2 January, I had the diagnosis that it's cancer. Completely ungraded, prognosis is unknown, stage is unknown. I couldn't believe it. I started chemotherapy two weeks after that, and had chemo booked once a week for 10 weeks, with an extra type every three weeks on top.

"The prognosis is we're going every 10 weeks for my life – we don't know.

"My life has changed dramatically – so drastically. I can't be on my own with my children. I was the other day for a bit, and it was lovely, and last night my husband was at football and I was with my youngest, who likes to do Lego on the landing.

"So I sat on the top step with him, but after about 10 minutes I had to go back downstairs. He's only six. I can't do the normal things that I would have done. It hurts. I'm in too much pain."



Martine Adams

After her diagnosis, Martine applied for Personal Independence Payments via the DWP.

“I get PIP now and had a Macmillan grant, and I think I could apply for mobility too, but I’m not sure. I can’t work, I’m not reliable enough, but I’m 28 and I don’t want to live the rest of my life on £600 a month. That’s not a living wage. I need money that is substantial to live.

“I remember ringing PIP, pressing the number for terminal because I had been

told it was terminal, and the lady on the phone said, ‘Hello, have you got six months or less to live?’ I said no, and she said, ‘Oh, well that’s what this is for.’ I remember questioning whether I was terminal, and I second guessed it.

“I spoke to my nurse and she said, ‘Yes, it’s like Alzheimer’s, dementia, MS. They are all terminal illnesses. That’s what you’ve got.’ I remember thinking it didn’t make any sense – you can’t tell someone when they’re terminal and then change it, which is what was happening.”

## CHAPTER FOUR

# Impacts of the current definition on terminally ill people

*“My partner only lived six weeks after diagnosis, during which time I cared for him – what should have been straightforward under the Special Rules became a nightmare at a very difficult time for us.”*

**W**hile many more people are living with terminal illness for longer, unfortunately this means that many people are also living with severe symptoms and disabilities for longer.

As the Association of Palliative Care Social Workers explained in its evidence, “people living with terminal illnesses and their families often encounter financial hardship for far longer than six months prior to death”.

The benefits system should be there to provide financial support to these families – but the six-month definition of terminal illness used in benefits legislation excludes many people who are likely to be living with terminal illnesses for longer than six months, or who are living with conditions that cannot be confidently predicted.

Without a DS1500 form allowing them access under the Special Rules, terminally ill people claiming under the Normal Rules face a significantly more complex, bureaucratic and time-consuming battle to get the benefits they need.

St Christopher’s Hospice described how “dealing with a clunky and opaque benefits system to get what may be essential basic financial support can feel impossible” for people living with the “devastating and far reaching” impact of a terminal diagnosis.

As large numbers of terminally ill patients are likely to ultimately be awarded the higher rate of disability support due to the nature of their conditions, there is nothing to be gained by forcing them down this route.

### Difficulties applying for benefits

*“My father had terminal bladder cancer – he was always nervous of bureaucratic processes and form-filling. It would have been the stuff my mum would have done.”*

Benefits claims under the Normal Rules for each of the Relevant Benefits require claimants to complete long and complex forms or make an application over the telephone, detailing their condition and symptoms, the details of their doctor or health worker and other medical information, as well as provide supporting documents to back up their claim.

The Personal Independence Payment application form, for example, is a complex multi-section application that runs to 33 pages, asking 15 multi-part questions (44 questions in total). The information booklet provided with the application is a further 12 pages and the guidance for individuals or organisations who support people who may be entitled to PIP is 47 pages long.

In its evidence to this inquiry, Citizens Advice noted that this process “can often be stressful and complicated” for people living with a terminal illness, especially if they have received their diagnosis recently. Difficulties that Citizens Advice clients face in making their applications include confusion about the benefits system and problems providing the evidence required for their claim by the Department for Work & Pensions (DWP).

Tenovus Cancer Care, similarly, explained how “the complex warren of the benefit application process is difficult enough under normal circumstances, let alone during this period of heightened distress”.

Citizens Advice also identified a particular problem for people who made claims under the Normal Rules prior to qualifying or becoming aware of the Special Rules. These claimants often see difficulties reporting changes in their circumstances to the DWP or having their claims moved on to the Special Rules process.

We have also been made aware of similar challenges faced by claimants living with terminal illness who are being migrated from older benefits to either the Personal Independence Payment or to Universal Credit.

### **Case study: DS1500 wrongly interpreted as evidence in a Mandatory Reconsideration**

The family of a person Citizens Advice helped in the South of England who was diagnosed with cancer made an application for PIP. This was denied in the weeks before she became eligible for a DS1500. Instead of fast-tracking the award, this was interpreted as evidence in a Mandatory Reconsideration, which delayed the period of time it took to make a decision.

In this case, the six-month definition meant the Special Rules fell in the middle of a terminal diagnosis.

Though her PIP was ultimately backdated, it meant stress and uncertainty while waiting several weeks for an award to be confirmed and a payment to be made.

## Requirement to attend assessments

*“My son died of a brain tumour at the age of 37, in 2016 – he was permanently worried about benefits and all the threats to assess him for work.”*

Claimants for each of the Relevant Benefits under the Normal Rules must attend a face-to-face assessment, at which their capability and eligibility for the benefit is assessed.

For people with a limited time to live, this process is overly time-consuming and insensitive, and it is not required of Special Rules claimants who have a DS1500 form from their clinician.

Assessments conducted under the Normal Rules process are based upon establishing the extent to which a claimant has difficulty performing everyday tasks or their immediate support needs, not on the condition they have.

There has been widespread criticism of DWP medical assessments in general and the Work Capability Assessment in particular, with the House of Commons Public Accounts Committee concluding that the process is inflexible and fails to account for rare or fluctuating conditions<sup>27</sup>.

Many terminally ill people are living with conditions that may not yet affect their capabilities, to the extent they have significant difficulties performing everyday tasks, but where their symptoms and frailty will progress over time. They can find that, after attending an assessment, they are

### Case study: Terminally ill patient denied Personal Independence Payments

One former carer told Dignity in Dying about her husband, who was diagnosed with advanced bowel cancer. He attempted to claim Personal Independence Payments (PIP) but was denied after assessment; he was unfit to work for over 18 months because of his treatment and was only granted PIP six months before he died, once his oncologist changed his prognosis to terminal.

He was constantly worried about money and even tried to return to work, even though he was not well enough to do so. His wife told Dignity in Dying that she now has stage 4 cancer herself and has not even attempted accessing benefits, because, based on her husband's experience, she is scared and anxious that she will be turned down.

awarded benefits at the lower rate or, in many cases, their applications are rejected entirely.

As outlined by the Motor Neurone Disease Association, there is a particular concern over the impact of exclusion from the Special Rules on Universal Credit claimants.

The Universal Credit customer journey does not include specific exemptions for claimants with disabilities or vulnerabilities.

As a result, people who are terminally ill but have more than six months to live and are forced to apply under the Normal Rules will be asked to attend work-focused interviews at a Jobcentre Plus with a work coach. This is in order to determine what work they can do and to agree a claimant commitment.

This is not only a waste of time and public resources, but demeaning and insensitive to a person who has had to give up work because of a progressive and terminal illness.

While many people with terminal conditions will ultimately end up in the Limited Capability for Work and Work-Related Activity (LCWRA) group under Universal Credit due to the nature of their condition, the National Association of Welfare Rights Advisers points out that it can take months for claimants to be placed into this group. During that time, work-related conditionality can still apply, and benefits will not be paid at the higher LCWRA rate.

Claimants applying via the Special Rules will not be expected to undergo any of these procedures. However, under the current rules, terminally ill people who may have more than six months to live are routinely exposed to inappropriate work coaching requirements.

In addition to the inappropriateness of assessments, it is wrong for terminally ill claimants to be awarded benefits at the lower rate or be denied benefits to which they should be entitled, based on the outcome of these assessments.

DWP statistics make the scale of this issue clear – between April 2013 and April 2018, 5,670 claims for the Personal Independence Payment were made under the Special Rules by people who had previously had at least one claim disallowed under the Normal Rules<sup>28</sup>.

Many of these people will have had a terminal diagnosis that did not meet the six-month definition at the time of their initial claim. Potentially, they will have spent several months without access to the full financial support they needed before finally meeting the six-month criteria and being able to get a DS1500 – 58% of such second claims were made within a year of the initial claim being turned down<sup>29</sup>.



**5,670**  
people have  
been awarded  
benefits under  
Special Rules  
after being  
turned down  
under the  
Normal Rules

## Delays receiving benefits

*“My partner lost his battle with MND three-and-a-half years ago and we had to wait eight months for any financial support. I cannot begin to describe how stressful it all was.”*

After an application has been made under the Normal Rules and claimants have attended an assessment, they are subject to long delays before a decision is made on their claim, followed by waiting periods before payments are eventually made.

These significant delays, over a period where the claimant may have limited or no other income, are wholly inappropriate for terminally ill people with a limited time left to live.

**It takes  
15 weeks  
on average for  
PIP decisions  
to be made  
under the  
Normal Rules**

For example, every application for Employment and Support Allowance under the Normal Rules is subject to a 13-week assessment period, while there is no set time period for the DWP to make a decision on a Personal Independence Payment claim. Under the Special Rules, decisions on PIP are typically made within five working days, but under the Normal Rules, it takes on average 15 weeks for a decision to be made<sup>30</sup>.

Many decisions will take significantly longer than this.

Even when a decision has been made, a Universal Credit claimant must wait a further five weeks before their first

payment is made. The “qualifying period” requirement for PIP and Attendance Allowance means that claimants can be made to wait for up to six months before their first payment is made – even after a decision to award the benefit.

The DWP has stated that terminally ill Universal Credit claimants who are in financial difficulty while awaiting their first payment can apply for an advance on their first payment like any other claimant<sup>31</sup>.

This will mean forcing terminally ill people to go through another bureaucratic application process, and ultimately leave them having their subsequent benefits payments cut to pay back the advance.

These delays take time that many terminally ill people simply do not have – and, for many people, the decision they ultimately receive comes too late. Between April 2013 and April 2018, over 17,000 people in Great Britain died while waiting for the DWP to make a decision on their PIP claim; an average of 10 people every day<sup>32</sup>.

Many of these people will have been terminally ill, but unable to make a fast-track claim through the Special Rules process due to not meeting the six-month definition.

In the vast majority of these cases, benefits were ultimately awarded, but the delays and waiting periods built in to the Normal Rules application process left those claimants without the financial support they needed in what turned out to be their final weeks of life.



## Kevin's story

### **Kevin Doonan talks about his mum, Carol, and the difficulty they experienced getting benefits when she was diagnosed with terminal cancer.**

“When Mum got her diagnosis, she asked me to help get her P45 from work and fill out the application for the Personal Independence Payment. It took me forever. I got to the point where I was thinking, ‘I don’t know what I’m going to do or how I’m going to get money for them.’

“Two weeks after she was diagnosed, when she was really bad, I was having a lot of trouble with the PIP. The DWP were asking her for face-to-face interviews. I had someone on the phone who said my mum needed to be sick for more than 12 weeks. You can get a diagnosis and be dead within a couple of weeks. My mum’s a perfect example of that.

“They wanted to come and interview her and speak to her on the phone, but my Mum could barely lift her arm. I didn’t

*“I remember when they rang to speak to my Mum. I told them she was basically unconscious. They asked me to wake her up. It was a terrible, terrible experience.”*

want her to deal with anything. I remember when they rang to speak to my mum. I told them she was basically unconscious. They asked me to wake her up. It was a terrible, terrible experience. They asked her questions like why she didn’t know she had cancer. They wanted to come and interview her face-to-face, which I objected to.

“It isn’t the person on the phone who makes up these rules and regulations. It’s somebody above them – but it was frustrating. They were asking her questions about the disease, how she didn’t know she had it, how this was going to affect her and why she left work so quickly. It was bizarre that they asked those questions, because she wasn’t a person that wanted to be off sick from work.

“She was going from full-time employment to minimum benefits, so there was a large drop in finances. I think they did fast-track her application, but it wasn’t fast enough because we had no money. She never got her first payment. She received the first payment after she was dead. I had to use my student loan to pay for things. I got my student loan in April and used that to pay for her funeral and everything like that.

“All my Mum was concerned about was the cost of the funeral, because the funeral overall was £5,500. She thought it was going smoothly because we didn’t want her to



know. I thought she didn't need to know, so I just told her everything was coming through fine. That was all we could do.

“I think the system failed her. This was somebody who paid her taxes, paid her dues, and should be fully entitled to receive a benefit. It wasn't much, it was a capped rate. It wasn't a lot compared to what she would have made in full-time employment.”

## Financial difficulties

*“My wife was terminally ill for over three years. We effectively lost everything we ever worked for and I am now left with debts of over £20,000.”*

Evidence from several organisations that work with terminally ill people, as well as testimony from family members, makes clear that being forced onto the Normal Rules process causes significant financial difficulty for claimants and their families, as well as considerable worry and distress.

The significant delays claimants experience while waiting for the DWP to make a decision on Normal Rules claims, as well as the further wait for payments to be made even after a claim has been awarded, can leave people living with a terminal diagnosis – who may have had to give up work and have no other income – in an impossible financial situation.

Terminally ill people in this situation face many of the well-documented issues caused by delays in the payment of benefits – falling into debt or rent arrears; relying on financial support from family or friends to cover their bills; and living with the constant stress and concern caused by being in financial difficulty – all while coming to terms with a terminal diagnosis.

For people on low incomes or on other means-tested benefits, the additional support provided by these benefits can be a significant proportion of their weekly or monthly income. Delays and challenges getting access to benefits can therefore

leave the families of terminally ill people in significant financial hardship.

Together for Short Lives explained how delays and challenges accessing benefits can lead to families “building a ‘debt legacy’ when trying to meet the associated costs of care”.

These challenges compound the financial pressures faced by many people living with severe and terminal conditions. Many families affected by terminal illness face significant additional financial burdens, including adaptations to the home or vehicles, additional heating costs, special diets and the cost of care.

Brain Tumour Research notes that, on average, families with a brain tumour patient are nearly £15,000 worse off a year. Similarly, the Motor Neurone Disease Association estimates the financial impact of living with MND is around £12,000 per year and Parkinson’s UK estimates people with Parkinson’s disease lose around £16,000 in income per year on average.

Quick access to benefits can help to alleviate these pressures, but being denied support will only exacerbate them further.

Worries about finances are not only deeply stressful for people living with terminal conditions – they can have a negative impact on a person’s health and prognosis.

Studies have shown how income is a predictive factor for quality of life for patients with advanced disease<sup>33</sup>. Patients in financial difficulty can have lower physical and emotional functioning, which can exacerbate and worsen their condition.

As the Royal College of Physicians told the APPG, for some patients financial support can make the difference between being able to cope while living and being cared for at home and needing to be admitted to hospital.

Similarly, the National Association of Welfare Rights Advisers told the APPG that it is impossible to overstate the impact that financial difficulties have on the lives and health of people living with terminal conditions who are unable to access benefits quickly and easily through the Special Rules.

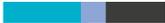
The financial problems caused by delayed access to benefits can multiply further; for example, as eligibility for Carer's Allowance is dependent on benefits like the Personal Independence Payment being in place, a delay in getting access to benefits can leave families facing a double strain on their finances if a family member is forced to

leave work to care for their terminally ill relative.

For the families of people living with many terminal illnesses, caring can quickly become a 24/7 role and many carers will rapidly need to give up work to do so, multiplying the financial burden on families.

According to the Carers UK State of Caring 2018 survey, 43% of carers looking after someone at the end of life said they were struggling to make ends meet financially<sup>34</sup>.

Delays in payment of benefits to terminally ill people, similarly, cause delays in being able to access non-financial support, such as Blue Badge and Motability, or receiving an increased rate of means-tested benefits, such as Housing Benefit, Council Tax reduction or tax credits.



**43%**  
of people  
caring for  
someone at  
the end of  
life say they  
struggle  
financially

### Case study: Terminally ill mother in London experiences familiar problems with Universal Credit

A single mother Citizens Advice helped, whose cancer returned after four cycles of chemotherapy, received a terminal diagnosis. She had recently been forced to stop working due to her illness. Since she has not got a DS1500 form, she has had to claim Universal Credit through the normal process. She has fallen into nearly £3,000 rent arrears, struggled with the wait for a payment and relied on friends and family to get by.

She previously worked, and only claimed tax credits and (recently) Statutory Sick Pay. Now, she cannot work and is spending a lot of time going in and out of hospital. She had no previous experience of the Work Capability Assessment, and is finding the process stressful, and her situation embarrassing.

In the worst cases, terminally ill claimants can find themselves denied benefits outright – whether through being rejected at assessment or having their claim denied for another reason.

Between April 2013 and April 2018, over 8,000 people died within six months of making a Personal Independence Payment claim that was denied by the DWP<sup>35</sup> – many of these people will have been terminally ill, but forced to claim through the Normal Rules due to not having a DS1500.

As Citizens Advice outlined in its evidence, terminally ill people in this situation can face weeks going through the Mandatory Reconsideration process and then going through the appeals process if deemed necessary – the timescales for an appeal averaged 30 weeks in October to December 2018<sup>36</sup>.

Throughout these months-long ordeals, terminally ill people and their families may be cut off from financial support entirely, with no guarantee of success at the end of the process.

## Reassessment after three years

*“Just because someone might live more than six months, doesn’t mean they are necessarily capable of living a normal life, of being assessed again.”*

Most people diagnosed with a terminal illness live for a matter of months or a small number of years. Only 39% of patients live for longer than a year with a brain tumour, for example, while a third of people with MND die within a year and more than half within two years.

A very small number of people are lucky enough to live for more than three years after they have been diagnosed as terminally ill. However, as benefit awards under the Special Rules are only made for three years, if a claimant is fortunate enough to reach this milestone, they must make an entirely new application or risk losing their benefits.

This will mean attempting to obtain a new DS1500 from their clinician for a Special Rules claim and, if they are not able to get a DS1500, facing the burdens outlined earlier in this chapter all over again.

Even though a minority of terminally ill people live for three years with their condition, their underlying need for financial support will not change.

Indeed, as the Royal College of General Practitioners told the APPG, in many cases,



Kate Stanworthy/Marie Curie

patients' needs will actually increase over time as progressive conditions cause increasing debility despite life-prolonging treatment, which may help them to live for more than the six months prescribed in law.

Requiring this small number of patients to go through the stress and burden of another benefits application after three years is inappropriate and insensitive, and leaves families at risk of losing their benefits, despite their conditions not having changed.

Elsewhere in the benefits system, the DWP has moved away from frequent

reassessments for people with severe conditions that are unlikely to improve, replacing them with a "light touch" review only every 10 years, at which point the Department will contact the claimant's doctor to confirm their condition remains the same.

For people living with terminal illness, every day matters and every day they live beyond their prognosis should be a cause for celebration. It is unnecessary and disproportionate for the DWP to force such a small group of people, whose needs are unlikely to have changed over time, to undergo a new application if they manage to outlive their original benefits award.

## Lorraine's story

**Lorraine Cox, 39, from Derrylin in Enniskillen, was diagnosed with motor neurone disease last summer. She applied for Personal Independence Payments to help with the impact of the disease on her day-to-day life and, to her shock, was declined.**

“From the moment I started the application process, I felt like I wasn’t being taken seriously. Just because I don’t look ill – I still wear make-up and dress well every day – that doesn’t mean that I’m less entitled. People don’t realise the impact MND can have on your life. It’s the little everyday things that become a struggle.

“I first started noticing something wasn’t right about 14 months ago. I went to the doctor, and then for an MRI scan, and was diagnosed pretty quickly after that. It came as a shock – you never think it’s going to happen to you.

“Now, I’ve completely lost the feeling in my left hand. I can’t make my own bed, my children help me get dressed, I have a cleaner, I can’t cook the way I used to. My

*“It has become a matter of principle, even above the money. I shouldn’t have to spend my time fighting for support. It’s exhausting.”*

balance is off, and I can now feel my foot starting to go too.”

As part of her PIP application, Lorraine had a face-to-face consultation with a Disability Assessor. It was after this that she was told her application had been declined.

“I felt so angry when I was assessed as not fitting the criteria. It’s very disheartening and I just don’t understand why it has to be so difficult. Work is very important to me as it gives me some independence and allows me to focus on something else. It’s a bit of escapism from my condition.

“But I want to reduce my hours next year, so I can spend more time with my kids. As I don’t have long, I want to spend quality time making memories. Looking ahead is the hardest part. I’ve started to have nightmares about my kids, a sense of loss or them being taken away from me. They have a wonderful father, but it’s not the same as having a mummy.

“I’m a very determined person and I’m not going to give up. It has become a matter of principle, even above the money. I shouldn’t have to spend my time fighting for support. It’s exhausting. Situations like this really make you realise what’s important in life and I’m very lucky that I have a good support network around me.



Marie Curie

“I felt I had to speak out about my situation as I don’t want others to have to face the same struggles at such a difficult time. The process needs to change and that’s why I think Marie Curie’s campaign to change the six-month rule is so important.

“I’m hoping that, in the future, things are made much easier for people and they can spend time with the people they love most, instead of fighting against an unfair system.”

## CHAPTER FIVE

# Concerns with the Department for Work & Pensions

*“Even though my mum had a DS1500 from her doctor, the DWP still wanted her to apply for Jobseeker’s Allowance.”*

Evidence to this inquiry shows that the Department for Work & Pensions (DWP) can challenge the decision of clinicians to provide a DS1500 for their patients even where their application and terminal diagnosis is supported by their doctors.

The Motor Neurone Disease Association reported that it had asked 21 health professionals for their experiences supporting Special Rules claims of the Personal Independence Payment for patients with MND – 13 said they had been contacted by DWP assessors questioning a prognosis they had given.

One said: “We have tried to complete DS1500 forms for people with MND previously and they have been rejected, because the PIP assessors have decided they are expected to live longer than six months.”

Similarly, MND Scotland said that clinicians who complete a DS1500 “often find their prognosis quizzed by the Independent Assessment Service (formerly Atos)”, and that their evidence is sometimes rejected.

Citizens Advice also told us that it had seen cases of decision-makers at the DWP incorrectly assessing claimants’ eligibility for the Special Rules.

The National Association of Welfare Rights Advisers explained that the DWP often does not contact the doctor who signed the DS1500 in such cases, instead simply notifying the claimant and leaving them to contact their doctor should they wish to challenge the decision and need more evidence.

This means that terminally ill people whose doctors felt they were entitled to access to benefits under the Special Rules based on their life expectancy have been forced to claim via the time-consuming, slow and uncertain Normal Rules process to access the financial support they needed.

The DWP recently confirmed that its policy is that it is possible for claims made under the Special Rules to be rejected as a Special Rules case by the assessment provider for not satisfying the terminally ill definition<sup>37</sup>, even where the claim is supported by a DS1500 issued by their clinician.

This policy is at odds with previous statements from ministers that the Special Rules “provide a guaranteed entitlement to benefit, with claims dealt with sensitively”, for terminally ill people<sup>38</sup>.

This means that non-specialist assessment provider staff are overruling the clinical judgment of clinicians who have first-hand knowledge of the claimant and their condition and who may have specialist clinical knowledge of the condition, excluding those claimants from the Special Rules process.

The National Association of Welfare Rights Advisers told the APPG that, frequently in such cases, a clinician's judgment will be overturned by assessors based on the assessor's understanding of the typical prognosis for a claimant's condition – overruling a medical professional with intimate knowledge of an individual's case in favour of a generalised figure from a prognostic table.

As outlined earlier in this report, many terminal illnesses are rare conditions and their progression is little understood, even by specialists, to the point that it is incredibly difficult to predict with certainty when a patient is approaching the end of life.

Brain Tumour Research pointed out that there are over 130 different identified brain tumours. Additionally, Parkinson's UK explained that terminal cases of atypical Parkinsonisms are often misdiagnosed – underlining the importance of clinicians having a good understanding of less common conditions when determining which cases are terminal and what a patient's prognosis may be.

We have heard evidence of the immense challenge faced by experienced clinicians in making a reliable prognosis for patients, even where they have detailed knowledge of their circumstances – and of the reticence of some clinicians to issue a DS1500 to a patient unless they are sure of their prognosis.

It is wholly inappropriate for the judgment of a clinician to be overturned by a DWP assessor with no first-hand knowledge of the claimant's case, based on a decision by that assessor that the claimant is likely to live longer than six months, especially in conditions where prognostic certainty is difficult to obtain.

This indicates that the six-month definition used in the law is being used in practice to exclude eligible terminally ill claimants from accessing the Special Rules process.

It is also unclear to the APPG why the DWP's policy is to rely on the clinical judgment of medical professionals to evidence whether a claimant meets this definition, by requiring a DS1500, only to overturn their judgment in practice.

## Recommendations

*"The current system is out of date. It is not appropriate for the population we see in front of us and it discriminates against people who need benefits."*

**Dr Sarah Cox, Royal College of Physicians**

The current legal definition of terminal illness is unfit for purpose.

The requirement that death can be "reasonably expected in six months" in order to allow a terminally ill person access to benefits under the Special Rules has no clinical meaning and is out of step with the reality faced by people living with terminal illness in the 21st century.

In 1990, Parliament's intention was to exempt terminally ill people from a rule that saw many of them unfairly and inadvertently denied the support they needed.

It is ironic that, 30 years later, the rule it introduced has had the unintended consequence of denying many more people the quick and easy "lifeline" they need.

Clinicians, charities, social and palliative care workers and medical experts who gave evidence to the APPG's inquiry agree that the current legal definition is outdated, arbitrary in nature, asks clinicians to make predictions that they cannot make with any degree of certainty, and leads to a meaningful inequality of access to benefits for terminally ill people.

The overwhelming majority of end of life care specialists surveyed by the Royal College of General Practitioners believe the current definition is unfit for purpose – the

Royal College of Nursing and Royal College of Physicians concurred and support reform.

The Association of Palliative Care Social Workers told us that they are "concerned the current legal definition of terminal illness will remain in place" given its impacts on patients, while Hospice UK said the definition "does not meet its intended purpose".

The distress, delay and financial difficulties faced by terminally ill people and their families waiting for benefits under the Normal Rules mean that this situation is not justifiable.

People living with a terminal illness should not be forced to spend the precious time they have in their last months of life grappling with the benefits system. Instead, they should be enabled to make the most of that time with friends and family, making memories and living as well as they can for as long as they have.

The APPG does not believe that the Department for Work & Pensions' decision to update its guidance for clinicians in April 2019 will sufficiently improve the experience of terminally ill people. While the "six-month rule" persists in law, it will continue to lead to terminally ill people being excluded from the fast-track access to financial support that should be rightfully theirs.

## Recommendation 1

We recommend that **the UK government amends the definition of terminal illness in UK law so that a person is determined as having a terminal illness if it is the clinical judgment of a registered medical practitioner or clinical nurse specialist that they have a progressive disease that can reasonably be expected to cause the individual's death.**

This will create parity across all nations of the UK and a much fairer system for terminally ill people, allowing them to get access to benefits via the Special Rules, where their clinician can certify that they have a terminal illness, without an arbitrary and clinically irrelevant timescale.

As outlined by the Association of Palliative Care Social Workers, this approach will also support clinicians to begin conversations about death and dying earlier with patients and their families, helping to support better care and advance planning – aligning with government objectives, such as those outlined in the Review of Choice in End of Life Care<sup>39</sup>.

The overwhelming majority of evidence submitted to the APPG's inquiry supports aligning the UK definition of terminal illness with the incoming Scottish law, both from a desire to avoid a two-tier system in Scotland and to ensure that the benefits system does not continue to fail terminally ill people in desperate need of financial support.

A majority of GPs told the Royal College of General Practitioners that they would support this change, with one concluding that this “would be welcomed by healthcare professionals, patients and their loved ones”.

Charities that work with terminally ill people, such as Marie Curie, the Motor Neurone Disease Association, Parkinson's UK, Brain Tumour Research, Together for Short Lives and Dignity in Dying, all support this reform, as do organisations that support benefit claimants, such as Citizens Advice and Advice Northern Ireland.

Cost may be a concern for government. According to the Institute for Fiscal Studies, in the long term, migration to Universal Credit will cut benefit spending by £2.7 billion a year<sup>40</sup>. In this context, any additional cost created by extending access to the Special Rules for a very small number of terminally ill people would be marginal.

Given that witnesses to the APPG's inquiry have identified that access to financial support can ultimately be the difference between patients being able to cope at home and needing to be admitted to hospital, the potential savings to the NHS of enabling more terminally ill people to claim easily should also be considered.

Madeleine Moon MP's Private Member's Bill, the Access to Welfare (Terminal Illness Definition) Bill 2017-19<sup>41</sup>, would address this recommendation and replicate the recent legal change made in Scotland. The APPG calls on all MPs to support this Bill.

## Recommendation 2

The present system of awarding benefits under the Special Rules for three years, and then requiring people with terminal illnesses to re-apply for benefits if they have lived longer than predicted, should also change.

The fact that a small number of people with terminal illnesses survive for longer than three years – giving them more time to spend with their family, friends and loved ones and more opportunities to live their lives as fully as they can for longer – should be celebrated, and not be a cause for further stress and anxiety.

Requiring people with terminal conditions, who have been awarded benefits under the Special Rules with a DS1500, to go through the entire application process again from the beginning if they are lucky enough to live with their condition for three years is burdensome, unnecessary and insensitive.

The DWP has already announced that it will end “unnecessary” benefit reviews for people with severe or progressive conditions<sup>42</sup> and replace these with a light-touch review after 10 years, to minimise the burden and bureaucracy faced by people with severe conditions that are unlikely to improve over time.

We recommend the DWP should adopt the same approach it has taken for severe conditions and **adopt a light-touch review of benefit awards under the Special Rules for Terminal Illness only after 10 years, with the DWP contacting**

**the claimant’s GP to confirm that their diagnosis and prognosis remains the same.**

This approach will spare the very small minority of people who are fortunate enough to live for three years with a terminal illness from having to unnecessarily re-apply for their benefits.

## Recommendation 3

The APPG is also greatly concerned to learn that non-specialist DWP assessors are frequently challenging the medical judgment of clinicians and overruling Special Rules claims for benefits, even where the clinician has provided a DS1500.

This practice is unjustifiable, gives lie to the DWP’s assertion that it treats the claims of terminally ill people with “the utmost sensitivity and care”<sup>43</sup>, and should be discontinued immediately.

We recommend that **the DWP ends the practice of non-specialist DWP assessors challenging and rejecting the medical evidence provided by clinicians in a DS1500 form to support a benefit claim under the Special Rules.**

Healthcare professionals, who know their patients’ cases and circumstances, must be able to exercise their clinical judgment as to whether a patient has a terminal illness without being second-guessed by DWP assessors in an attempt to exclude those patients from access to benefits.



## Inquiry terms of reference and witnesses

The APPG launched a call for evidence in March 2019, seeking evidence from organisations, stakeholders and individuals with relevant expertise and experiences with the legal definition of terminal illness. The terms of reference for this call for evidence were:

1. For the purpose of gaining fast-track access to benefits, is the current legal definition of being terminally ill as having six months left to live fit for purpose?
2. Does the six-month definition help or hinder people affected by terminal illness to receive the support that they need?

The APPG heard oral evidence from the following witnesses:

### Tuesday 4 June

Mark Hazelwood, *Chief Executive at the Scottish Partnership for Palliative Care*

Dr Catherine Millington-Sanders, *End of Life Care Champion at the RCGP*

### Wednesday 5 June

Prof. Patrick Stone, *Professor of Palliative Medicine at the Marie Curie Palliative Care Research Department, University College London*

Daphne Hall, *Vice Chair at the National Association of Welfare Rights Advisors*

### Thursday 6 June

Alex Massey, *Policy Manager at the Motor Neurone Disease Association*

Dr Sarah Cox, *Consultant in Palliative Medicine and Chair of the RCP/APM joint speciality committee*

Michael Griffin, *Senior Policy and Campaigns Adviser at Parkinson's UK*

Erika Murigi, *Head of Public Affairs and Campaigning at Brain Tumour Research*

Transcripts of the oral evidence sessions are available on the Marie Curie website at [www.mariecurie.org.uk/policy/appg-for-terminal-illness](http://www.mariecurie.org.uk/policy/appg-for-terminal-illness)

The APPG received expert written evidence from the following organisations and individuals:

Advice Northern Ireland; Anne Marie Marley; Anne-Marie Rafferty; Association of Palliative Care Social Workers; Brain Tumour Research; Children's Hospices Across Scotland; Citizens Advice; Dignity in Dying; Dr Clare Gardiner; Dr Stephen Marshall; Dr Timothy Williams; Health and Social Care Alliance Scotland; Hospice UK; Law Centre (NI); Maggie's Glasgow; Marie Curie; MND Scotland; Motor Neurone Disease Association; Parkinson's UK; Royal College of General Practitioners; Royal College of Nursing; Royal College of Physicians; Scottish Partnership for Palliative Care; Social Democratic & Labour Party; St Christopher's Hospice; Tenovus Cancer Care; Together for Short Lives.

Unless otherwise stated, all quotes and statistics featured in this report are from evidence submitted to the APPG's inquiry, or from experiences shared with Marie Curie.

## References

- <sup>1</sup>Welfare Reform Act 2012 s82(4)
- <sup>2</sup>Social Security Act 1990, s1
- <sup>3</sup>HL Deb 22 June 1989, vol 509
- <sup>4</sup>HC Deb 22 January 1990, vol 175
- <sup>5</sup>Social Security Advisory Committee, Benefits for Disabled People: A Strategy for Change, 1988
- <sup>6</sup>HL Deb 22 June 1989, vol 509
- <sup>7</sup>HC Deb 22 January 1990, vol 175, col 628
- <sup>8</sup>DWP Medical (factual) reports: A guide to completion
- <sup>9</sup>Social Security (Scotland) Act 2018, Schedule 5 para 1(2)
- <sup>10</sup>Independent Review of the Personal Independence Payment (PIP) Assessment Process in Northern Ireland
- <sup>11</sup>All-party letter to Northern Ireland Department of Communities, 18 June 2018
- <sup>12</sup>Treatment and Care Towards the End of Life: good practice in decision making, GMC 2010
- <sup>13</sup>'Row over benefits for terminally ill patients,' The Times, 19 April 2018
- <sup>14</sup>Motor Neurone Disease Association
- <sup>15</sup>Smith et al (2017), Prognostic variables and scores identifying the end of life in COPD: a systematic review
- <sup>16</sup>Tapsfield et al. (2016) 'Many people in Scotland now benefit from anticipatory care before they die: an after death analysis and interviews with general practitioners'
- <sup>17</sup>White N, Reid F, Harris A, Harries P, Stone P (2016), A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts?
- <sup>18</sup>Christakis N and Lamont E (2019) 'Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study
- <sup>19</sup>White et al. BMC Medicine (2017)
- <sup>20</sup>DWP Medical (factual) reports: A guide to completion
- <sup>21</sup>White N, et al. BMJ Supportive & Palliative Care (2019)
- <sup>22</sup>medeConnect survey on behalf of the Motor Neurone Disease Association, October 2018
- <sup>23</sup>ibid
- <sup>24</sup>DWP statistics, May 2019
- <sup>25</sup>Northern Ireland Department of Communities, FOI data
- <sup>26</sup>Northern Ireland Statistics and Research Agency (NISRA), Registrar General Annual Report 2017
- <sup>27</sup>Public Accounts Committee, 'Department for Work and Pensions: Contract management of medical services', 23 January 2013, HC744
- <sup>28</sup>HC Deb 4 February 2019 Vol 654 209781W
- <sup>29</sup>ibid
- <sup>30</sup>DWP statistics, March 2019
- <sup>31</sup>HC Deb 22 October 2018 Vol 648 178221W
- <sup>32</sup>DWP statistics, April 2019
- <sup>33</sup>Roick J et al (2019), 'The association of socioeconomic status with quality of life in cancer patients over a 6-month period using individual growth models'
- <sup>34</sup>State of Caring 2018, Carers UK
- <sup>35</sup>DWP statistics, April 2019
- <sup>36</sup>Moj statistics, March 2019
- <sup>37</sup>HC Deb 30 April 2019, vol 659, WA 245707
- <sup>38</sup>HC Deb 20 December 2017, vol 633, WA 120775
- <sup>39</sup>Review of Choice in End of Life Care
- <sup>40</sup>The (changing) effects of Universal Credit, Institute for Fiscal Studies, June 2016
- <sup>41</sup>Access to Welfare (Terminal Illness Definition) Bill 2017-19
- <sup>42</sup>Government to end unnecessary PIP reviews for people with most severe health conditions
- <sup>43</sup>Letter from Justin Tomlinson, Minister of State for Disabled People, Health and Work to House of Commons Work & Pensions Committee, 8 April 2019



**For more information:**

**Marine Paclet**

APPG for Terminal Illness secretariat

E: [marine.paclet@mariecurie.org.uk](mailto:marine.paclet@mariecurie.org.uk)