Neutral Citation No: [2021] NICA 46 *Judgment: approved by the Court for handing down (subject to editorial corrections)**	*Ref:* **MOR11583** *ICOS No:* **19/116363/01/A01 19/116363/01/A02** *Delivered:* **03/08/2021**

IN HER MAJESTY'S COURT OF APPEAL IN NORTHERN IRELAND

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ON APPEAL FROM THE HIGH COURT OF JUSTICE IN NORTHERN IRELAND QUEEN'S BENCH DIVISION (JUDICIAL REVIEW)

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THE DEPARTMENT FOR COMMUNITIES
and
THE DEPARTMENT FOR WORK AND PENSIONS

Appellants

and

LORRAINE COX

Respondent

_____

Dr McGleenan QC and Mr McAteer (instructed by Crown Solicitor) for the Appellants
Ms Quinlivan QC with Mr McGowan (instructed by the Law Centre (NI)) for the Respondent

_____

Before: Morgan LCJ, Treacy LJ and McCloskey LJ

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MORGAN LCJ (delivering the judgment of the court)

[1] The Special Rules on Terminal Illness ("SRTI") prescribe the mechanism in the social security system for the payment of Personal Independence Payment ("PIP") and Universal Credit ("UC") benefits without assessment to those who satisfy the definition of "terminally ill". That definition requires that a person is suffering from a progressive illness where death in consequence of that disease can be reasonably expected within six months.

[2] McAlinden J found that the respondent, Lorraine Cox, suffered from a progressive illness but had a reasonable expectation of surviving for more than six months. He concluded that this was a "status" for the purposes of Article 14 of the European Convention on Human Rights ("the Convention") and that those with that status were analogous to those individuals with a terminal diagnosis who were

reasonably expected to die within six months as a consequence of that illness but who survived beyond that six month period. The latter group were entitled to benefits without assessment whereas the former, of which the respondent was a member, had to go through an assessment process. He found the difference in treatment was not justified and constituted a breach of Article 14 of the Convention within the ambit of Article 8 and Article 1 Protocol 1 ("A1P1"). He concluded that the relevant provisions could not be read and given effect in a way which was compatible with the Convention rights and awarded the respondent £5000 by way of just satisfaction.

[3] The appellants, The Department for Communities ("DfC") and the Department for Work and Pensions ("DWP"), accept that the provision of the benefits is within the ambit of Article 8 and A1P1 of the Convention. They contend that the trial judge erred in respect of his assessment of status, the analogous group and justification. By a Respondent's Notice the respondent submits that the award of just satisfaction was inadequate and further submits that the decision of the judge should be upheld for these additional reasons:

(a) the appellants discriminated against the respondent contrary to Article 14 in conjunction with Article 8 and A1P1 by treating her differently than others in an analogous situation, namely individuals suffering from a terminal illness with a predictable trajectory, without justification;

(b) the appellants discriminated against the respondent contrary to Article 14 in conjunction with Article 8 and A1P1 by treating her equivalently to individuals in a relevantly different situation, namely individuals without a terminal illness, without justification.

Legislative Background

[4] Social security is a devolved matter but there are particular arrangements for consultation and co-ordination in section 87 of the Northern Ireland Act 1998:

> "**87 Consultation and co-ordination**
>
> (1) The Secretary of State and the Northern Ireland Minister having responsibility for social security ("the Northern Ireland Minister") shall from time to time consult one another with a view to securing that, to the extent agreed between them, the legislation to which this section applies provides single systems of social security, child support and pensions for the United Kingdom.
>
> (2) Without prejudice to section 28, the Secretary of State with the consent of the Treasury, and the Northern

> Ireland Minister with the consent of the Department of Finance and Personnel, may make—
>
> (a) arrangements for co-ordinating the operation of the legislation to which this section applies with a view to securing that, to the extent allowed for in the arrangements, it provides single systems of social security, child support and pensions for the United Kingdom; and
>
> (b) reciprocal arrangements for co-ordinating the operation of so much of the legislation as operates differently in relation to Great Britain and in relation to Northern Ireland.
>
> (3) Such arrangements as are mentioned in subsection (2)(a) or (b) may include provision for making any necessary financial adjustments, other than adjustments between the National Insurance Fund and the Northern Ireland National Insurance Fund."

[5] These arrangements reflect the parity principle which governs the funding of Northern Ireland through the block grant for social security purposes. If the Northern Ireland legislature introduces more generous arrangements the block grant is not automatically adjusted to fund those matters so that the funding must be secured from other elements of the block grant. Unsurprisingly the statutory provisions governing the social security benefits with which this case is concerned broadly reflect the parity principle.

[6] Social security provision for those who are terminally ill was first made in December 1971 with the introduction of Attendance Allowance ("AA"). This was a non-means tested universal disability benefit directed to those who had a serious or debilitating illness or disability and required personal assistance. The benefit was payable only if the person concerned had required attendance as a result of a disability or health condition for a period of at least six months. The underlying intention was that the benefit would be payable only in circumstances where the condition was likely to endure for the longer term.

[7] In 1988 the Social Security Advisory Committee ("SSAC"), an independent quango, conducted a study of benefits for disabled people. In their ensuing report to government they identified various "defects … (which) … affect quite small numbers of people but some are people who are particularly disadvantaged." One of the cohorts thus identified was the terminally ill. The report stated:

> "We have been told that there is a small number of people, mostly suffering from the terminal stages of

> cancer, whose life expectancy is predictable and will probably be less than six months. These people require a great deal of care. We believe that the cost of attendance allowance would not be greatly increased if, as an alternative to serving the qualifying period, these claimants' doctors could certify that they would continue to require attendance for at least six months or for the rest of their lives. We recommend that people claiming attendance allowance who are terminally ill should become entitled to attendance allowance immediately."

The SSAC recommended that the definition of "terminally ill" in the DHSS circular HC(87)4 be adopted. This was:

> "The terminally ill patient is one whose death is certain and not too far distant and for whom treatment has changed from curative to palliative."

The report noted that this definition applies <u>mainly</u> to patients suffering from terminal cancer.

[8] The Social Security Bill (1989) followed. This was debated in the House of Lords on 22 June 1989. The debate ranged over *inter alia* the SSAC's recommendation to abolish the six month qualifying period for AA in order to facilitate the terminally ill. Contributors to the debate highlighted that the vast majority of patients who reach the terminal phase of cancer, AIDS and similar illnesses survive for substantially less than six months and thus, never qualify for the benefit. An average period of nine weeks survival was suggested. Supporting the amendment Lord Mottistone stated (Col 358):

> "The amendment draws a tight definition of those who will benefit. They must be suffering from severe and progressive incurable disease. They must be receiving palliative care … my amendment will apply only to patients in the last weeks or months of life and who are so severely ill that they will never make the six month gateway."

The Government's willingness to alter the law in this way was confirmed when the Secretary of State for Social Security made an "uprating of social security benefits" statement in the House of Commons on 25 October 1989, which included the following (Col 848):

> "… attendance allowance will be made available to the terminally ill without the normal six months waiting

> period. That is expected to help more than 50,000 people by up to £37.55 a week."

[9] In January 1990 the Government published "The Way Ahead – Benefits for Disabled People" (Cm 917). This confirmed the adoption of a new legislative policy abolishing the six month qualifying period for AA in respect of the terminally ill. At the second reading of the Social Security Bill in the House of Lords, on 20 April 1990, the Parliamentary Under-Secretary of State proclaimed that the new legislation –

> "… will ensure that people who suffer from a progressive disease and for whom death in consequence can reasonably be expected within six months will be able to qualify for attendance allowance without having to satisfy the normal six month qualifying period …About 58,000 each year will benefit."

Later contributions to the debate emphasised that the proposed reform had been preceded by wide ranging consultation with, *inter alia*, organisations representing hospices, hospice social workers, the British Medical Association and those specialising in palliative care. A specially tailored claim form and leaflet were to be introduced. During debates the difficulty of predicting survival periods for certain patients was highlighted.

[10] The newly adopted legislative policy was reflected in section 1 of the Social Security Act 1990 and the amendment of section 35 of the Social Security Act 1975, by creating a new section 35(2C)(a) containing the following definition of "terminal illness":

> "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."

The next major statutory measure was the Social Security Contributions and Benefits Act 1992. This contained, without amendment, the aforementioned definition of "terminal illness", in section 66(2). This definition applied to both AA and Disability Living Allowance ("DLA"). This definition was employed again in the Social Security (Incapacity for Work) Act 1994, per section 2(1). By this stage, it would appear, the shorthand, or jargon, was "SRTI."

[11] In January 2004 the Minister for Disabled People requested the DLA Advisory Board ("DLAAB") to undertake a study of the SRTI for AA and DLA. The DLAAB is a statutory body which advises government. The impetus for this review was the developing concern relating to the longer than expected survival periods of successful claimants. Nothing of any major significance ensued. The DLAAB, in its resulting report, fully endorsed the principle of special rules for the beneficiary

cohort; opined that the system was generally operating well; and proposed the introduction of a review mechanism in respect of successful claimants whose survival continued for years following their award. No recommendation was made about the definition of "terminal illness."

[12] The continued adoption of the SRTI definition of "terminal illness" was reflected in subsequent statutory measures such as regulation 2(1) of the Employment and Support Allowance Regulations 2008 and regulation 2(1) of the Employment and Support Allowance Regulations 2012, each of which was concerned with the newly introduced Employment and Support Allowance ("ESA") which replaced Incapacity Benefit in 2008.

[13] In December 2010 the Government published its public consultation paper "Disability Living Allowance Reform" (Cm 7984). This heralded a proposed new legislative policy, reflecting major social policy reform, which had two central elements. First, PIP would be introduced replacing DLA. Second, UC would be introduced, replacing a series of so-called "legacy" benefits. The policy drivers were making work pay, tackling fraud and error and simplification of a highly complex benefits system. This was subsequently reflected in the Welfare Reform Act 2012 and a series of associated measures of subordinate legislation. Regulation 2 of the Universal Credit Regulations 2013 defined "terminally ill" as –

> "… suffering from a progressive disease where death in consequence of that disease can reasonably be expected within six months."

[14] PIP was, simultaneously, introduced by statute in 2013. It replaced DLA for working age people. DLA had been introduced in 1992, effecting a merger of the two pre-existing benefits of AA and Mobility Allowance. It provided a cash contribution towards the extra costs of needs arising from certain medical impairments or health conditions. It was non-means tested, payable irrespective of employment status and was non-taxable. PIP replicated these features. It was designed, in particular, to ensure the provision of financial assistance to those in greater need and to provide a more consistent and transparent model.

[15] During this period of devising statutory reforms the mechanism of the SRTI was specifically considered. A submission to the DWP Minister in August 2010 contained the following revealing passage:

> "We automatically award all SRs cases with higher-rate care because life expectancy is normally so short and health deterioration expected to be so rapid that it would be operationally inefficient and distressing for the customer to continually review the award for changes in need. We universally and equally maximise the help we can provide people, in anticipation of the extreme care

> needs that are likely to occur before death. To alter the SRs criteria would, therefore, add extra and difficult case management, constant/frequent reviews for minimal AME savings and be understandably very unpopular with customers and their carers."

A later passage in the submission specifically addressed the issue of certain groups who were excluded from the SRTI:

> "Whilst the normal qualifying rules are waived for people who are terminally ill we have, in the past, been pressed to extend the qualifying rule waiver to, amongst others, injured service men, children and people diagnosed with cancer or others with serious progressive diseases and undergoing treatment (not expected to fit the strict SR criteria). Whilst we could exempt such categories of people, to do so could expose us to irresistible pressure to extend this concession to all, or at least wider groups of, disabled people. This would come at additional AME cost and could be paid to people who are not long-term disabled. These people do continue to have access to our disability benefits in the normal way ….
>
> Additionally, there has also been pressure to extend the definition of SR i.e. lengthen the terminal illness threshold from six months much further e.g. nine, twelve months or even years. Whilst this might be a worthy idea for a larger group of people with a slightly longer but still relatively short life expectancy, the costs of using the passporting rate of highest rate care would increase AME costs considerably. There is also a risk we would be awarding a rate of benefit that might not be consistent with their care needs or accurately reflect their extra costs."

Giving effect to this reasoning, the civil servant author recommended to the Minister the perpetuation of the *status quo*.

[16] The SSAC is one of the agencies which responded to the DLA reform consultation. Its submission contained a passage recommending the maintenance of the SRTI:

> "SSAC agrees that the special rules, and the status of the benefit as non-means tested, non-taxable and non-contributory, should continue. We would like to see the benefit continue to be exempt from being counted as income for the purpose of means-tested benefits and for it

> to continue to act as a passport to higher rates of means tested benefits."

The legislative measures introducing UC and PIP were the Welfare Reform Act 2012 and, amongst other subordinate measures, the Universal Credit Regulations 2013 (the "2013 Regulations"). Regulation 2 of the latter instrument employed the now established definition of "terminal illness". This definition was further perpetuated in Article 87 of the Welfare Reform (Northern Ireland) Order 2015 ("the 2015 Order") and in regulation 2 and paragraph 1 of Schedule 9 to the Universal Credit Regulations (Northern Ireland) 2016. The effect of these two last mentioned provisions, each having the status of subordinate legislation, is that a person applying for either UC or PIP on the ground of terminal illness must satisfy the criterion that death as a consequence of the illness can reasonably be expected within six months. These two statutory provisions are the focus of the challenge in these proceedings.

Policy discussion

[17] The 2015 Order contained a mechanism for statutory review of PIP every three years. The first statutory review was carried out by Walter Rader and his report was published in June 2018. Although the report was directed to the Northern Ireland Executive that body had ceased to function in January 2017 and did not sit again until January 2020.

[18] Chapter 8 addressed the discrete topic of the terminally ill and the SRTI. The author noted that short life expectancy claimants could avail of an expedited paper-based assessment supported by the completion of Form DS1500 by a medical practitioner. The bureaucratic assessment process was completed within one week in practice. Resulting awards had a three year lifespan. The relevant section of the report continued:

> "The Review has listened carefully to the concerns expressed regarding the application of special rules and the impact the diagnosis of a terminal illness can have. The Review is of the opinion that the determining factor, as to how these sensitive cases are processed, should be the provision of a clinical judgement indicating a terminal condition. This should be sufficient to allow for special rules to be applied."

This was followed by "Recommendation No 6":

> "That the clinical judgement of a medical practitioner, indicating that the claimant has a terminal illness, should be sufficient to allow special rules to apply. The six months life expectancy criterion should be removed. This

> will lessen pressure, stress and anxiety on claimants and their families at what is an already difficult time."

[19] In November 2018 DfC published its interim response noting that the review in 2010 found that the majority of respondents indicated that the SRTI worked well and should remain the same. It would be for incoming Ministers to determine if they wish to initiate any review of the current arrangements in place of the special rules in Northern Ireland, taking account of the position in Great Britain.

[20] In July 2019 the All-Party Parliamentary Group for Terminal Illness ("APPG") published "Six months To Live", a study and commentary on the legal definition of "terminal illness." The conclusions of the report were clear:

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

[21] The Foreword noted that since 2013 at least 17,000 people had died while awaiting the payment of benefits to which they were rightly due and continued:

> "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."

[22] The APPG report also identified some relevant 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". 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.
>
> 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 judgement of a registered medical practitioner that the individual has a progressive disease that can reasonably be expected to cause the individual's death.
>
> 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 on an arbitrary six-month timescale."

Scotland

[23] The review of the operation of the SRTI in Scotland dates from around 2016. In February 2018, in the context of the evolving Social Security Bill, a proposal was mooted that claimants with a terminal illness would be entitled to disability assistance at once where death was expected within a period of two years. Following further consultations this proposal did not advance. When Stage 3 of the Bill was debated on 25 April 2018 the Scottish Parliament adopted an amendment which prescribed no timeframe, simply providing for statutory guidance to medical practitioners to make determinations on terminal illness for the purposes of accessing benefits under SRTI, based on their clinical judgement, to be developed by the Chief Medical Officer. This was described by the Social Security Minister as the "most challenging issue" that had arisen in the development of the Bill. The guiding principle of "providing for maximum clinical judgement" was articulated.

[24] This amendment was approved. It is reflected in paragraphs 1(2) and (3) of Schedule 5 to the Social Security (Scotland) Act 2018 ("the 2018 Act"). These provisions give primacy to the principle of clinical judgement, which is to be formed

by a registered medical practitioner "having had regard to" the Chief Medical Officer's guidance. The latter must set out:

> "… when a progressive disease can reasonably be expected to cause an individual's death for the purpose of determining entitlement to disability allowance."

The Act received Royal Assent on 1 June 2018. Subsequently, by section 11 of the Social Security Administration and Tribunal Membership (Scotland) Act 2020, registered nurses were added to the group of those qualified to make the requisite clinical judgement.

[25] The Department's updated submission indicated that the Scottish Chief Medical Officer, having consulted with medical professionals and stakeholder groups, had developed the requisite statutory guidance. This was eventually published in July 2021 after the hearing of this case. Each party was given an opportunity to submit comments on the Guidance. PIP, DLA, Child and AA are the only devolved benefits affected by the Guidance. The position for UC remains as in the rest of the UK. The Guidance provides for the decision on fast track access to PIP on the basis of terminal illness to be based on the clinical judgment of an appropriate health care professional, taking account of a set of specified clinical indicators.

[26] The Executive Summary of the APPG report indicates that it is not expected that every person in Scotland 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 Guidance reflects that expectation. In order to qualify for the SRTI the patient must display the following indicators:

(a) an illness that is advanced and progressive, or with risk of sudden death, AND

(b) that is not amenable to curative treatment, or treatment is refused or declined by the patient for any reason, AND

(c) that is leading to an increased need for additional care and support.

[27] Although the Guidance indicates that it is not for the healthcare professionals to assess the type of disability benefit for which the plaintiff is eligible or to undertake a formal functional assessment it is necessary for the healthcare professional to make a judgement about the need for additional care and support. The Guidance recognises that in certain cases estimating the prognosis will be challenging. Annex C of the Guidance provides some worked examples. One of those is in respect of Motor Neuron Disease ("MND") (rapid decline in condition). The indicators are that the patient had been diagnosed, had lost much of the use of his hands and was walking with a limp. It was anticipated that he would soon need to use a wheelchair. In those circumstances he met or surpassed the need for

additional care or support. The effect of this arrangement, therefore, is effectively in the case of a progressive illness such as MND to make the assessment of need leading to the highest rate of PIP benefits a clinical judgement rather than an administrative exercise.

Northern Ireland

[28] On 06 October 2020 the Northern Ireland Assembly ("NIA") adopted a resolution: welcoming the Rader Report recommendation of the abolition of the six month life expectancy criterion; recognising the "significant evidence and support" from a wide range of local stakeholders for reforming this rule; acknowledging the recent creation of a NIA all-party group on terminal illness; and exhorting the Minister for Communities to "immediately" bring forward legislation abolishing the rule, providing guidance to health professionals and adopting a fairer definition of terminal illness.

[29] This was followed by the second independent PIP review. This report, as noted above, was the second of the two reports required as a matter of obligation consequent on the passing of the 2015 Act. This notes that while DfC had responded positively to 10 of the 14 recommendations in the predecessor report, full implementation was still distant. It said the following of SRTI:

> "This Review has received evidence which continues to support the removal of the 'cruel and arbitrary' six month rule. The Review has received evidence from a number of advocacy groups, medical professionals and political parties calling for the definition of terminal illness to be amended …
>
> The Review has heard evidence highlighting the Scottish Government approach to SRTI claims as an example of what can be done in a regional basis with devolved matters."

Amongst the report's recommendations is the following:

> "Given the substantial supporting evidence gathered during the second Review, the Review recommends the Department revisits Recommendation 6 from the first Review that the six months life expectancy criterion for terminally ill claimants should be removed and replaced with a system based on clinical judgement similar to that enacted by the Social Security (Scotland) Act 2018. This should include adopting a subsequent ten year light touch review on awards made where special rules apply."

An example of the supporting evidence is provided by a letter dated 15 December 2020 from the Royal College of General Practitioners for Northern Ireland to the DfC Minister.

[30] A helpful update on funding was provided in the further written submission from the Department's legal representatives:

> "The £2 million estimated figure detailed here relates only to a part-year cost for the latter half of 2021/22. When final decisions have been taken in relation to the 2021/22 budget, the Department will consider the available options."

The further data provided to the court indicates that the "main disabling condition" of 40 current benefits claimants is MND. Of these, ten have been processed under SRTI, while the remaining 30 are the subject of the normal rules.

[31] Subsequent to the hearing in this case the DfC Minister announced on 30 June 2021 an intention to replace the six month time frame with a period of 12 months within which death can reasonably be expected. The Minister stated that it was her intention to implement this change before the expiry of the current mandate in May 2022.

Department of Work and Pensions

[32] The position of the DWP at the time of the hearing was set out as follows:

> "DWP is committed to delivering an improved benefit system for claimants that are nearing the end of their lives and is working across Government to bring forward proposals following the evaluation. DWP has not been able to bring forward these changes as soon as it would have wished but unfortunately responding to COVID-19 and its impacts has delayed publishing the outcome of the evaluation."

It was accepted by the respondents that the policy debate included extending the time limit to 12 months or dispensing with it altogether and replacing it with a clinical assessment. On 8 July the DWP Minister confirmed that the UK Government intends to extend the time period from 6 months to 12 months.

Personal Independence Payment

[33] PIP is a non-contributory, non-means tested and tax-free Social Security benefit payable under Part 5 of the 2015 Order. It is paid to help with the extra costs associated with a long-term health condition or disability. Entitlement to PIP is not

based on an individual's condition, but on how the person is affected by it and how they participate in society.

[34] PIP is made up of two components. One is assessed by reference to daily living needs and one assessed by reference to mobility. Entitlement is determined through an assessment of a person's ability to carry out a range of key everyday activities considered necessary to participate in daily life. Each component is payable at the standard or enhanced rate. Claimants must have needed help for three months or more (this is known as the qualifying period) and be likely to need help for the next nine months (this is the prospective test period). Together these are referred to as the "required period condition" and helps establish that the health condition or disability is likely to be long-term.

[35] The respondent is a 40 year old mother of three children. In 2017 she experienced reduced feeling in her left hand. In September 2017 she attended her GP and was referred for an urgent neurological opinion. On 7 March 2018 she made a claim for PIP. Her claim was refused on 25 July 2018 and she sought a mandatory reconsideration on 9 August 2018.

[36] Later that month she received a confirmed diagnosis of MND. That is a neurological condition in which motor neurons gradually stop telling muscles how to move. This impacts upon an individual's ability to walk, talk, eat, drink and breathe. One third of patients with MND will die within a year of diagnosis and half within two years. However, as a result of the current level of understanding of MND it is very difficult for clinicians to accurately predict which MND patients are likely to die sooner than others and it is not possible to give a precise prognosis of life expectancy in individual cases.

[37] The respondent was awarded PIP (Daily Living) at the standard rate from 7 March 2018 to 3 July 2021 on 16 November 2018. This was a lower rate than she would have received under the SRTI. Her appeal was refused on 3 April 2019. She submitted a further claim on 4 May 2019 noting her diagnosis. The level of benefit was not altered but the period extended from 10 September 2019 until 1 January 2022. In November 2019 she reported a further change of circumstances and requested a mandatory reconsideration of the earlier decision. On 24 November 2019 she was awarded PIP (Daily Living) at the enhanced rate and PIP (Mobility) at the Standard Rate from 9 April 2019 to 1 January 2022. That was the same rate that she would have received under the SRTI but it was time-limited.

[38] On 16 January 2020 the respondent submitted a DS1500 form from her consultant. That is a form made available for doctors to support applications for SRTI benefits. The consultant had not confirmed a reasonable expectation of death within six months and was contacted by DfC. The consultant explained that she was not aware that there was a six month limit in cases of this type and she indicated that she did not consider that there was a reasonable expectation of death as a consequence of MND within six months in this case.

[39] In a medical report to the respondent's solicitors dated 5 August 2019 the consultant stated that the definition of terminal illness is very restrictive and she supports the efforts to try to improve it. She said that the respondent had young onset disease and the tempo of MND in younger patients was often slower but not always. She stated that she would need to see her again to get a feel for the tempo of her condition. The consultant stated that the average survival from MND is 3 to 5 years but this varies considerably and giving definitive predictions of prognosis is not possible. On 19 February 2020 DfC decided that the respondent was entitled to PIP (Daily Living) at the enhanced rate and PIP (Mobility) at the enhanced rate for an ongoing period.

Universal Credit

[40] UC is payable under Part 2 of the 2015 Order. It is a single welfare payment which replaces a range of legacy benefits – Child Tax Credit, Housing Benefit, Income Support, Income-based Jobseekers Allowance, Income -related Employment and Support Allowance and Working Tax Credit. It is made up of a standard allowance and any extra applicable amounts (for example, people too ill to work). The purpose of UC, like other welfare benefits, is to further a wide range of social policy objectives, including assisting those with no or low incomes. UC is not designed to provide a complete indemnity against individual needs. UC constitutes a highly variable payment which takes into account different aspects of an individual's personal circumstances. It is intended to adjust to changes in those circumstances.

[41] On 4 March 2019 the respondent claimed UC. She stated that her condition was "Motor Neurone Disease" and prognosis "2-5 years." The following day DfC determined that the conditions in relation to terminal illness were not satisfied as the respondent's evidence indicated that the prognosis was more than 6 months. If the respondent had qualified under the SRTI she would have been treated as having limited capability for work related activity ("LCWRA"). She eventually succeeded in establishing her entitlement to UC (LCWRA) on 6 September 2019 thereby adding £336.20 to her monthly UC award. Between March and September 2019 she was required to attend various meetings with the work coach as part of the requirement to undertake work-related activity pending a three-month work capability assessment. It appears that appointments were missed and interviews had to be rearranged. The Law Centre intervened on her behalf.

The meaning of "terminal illness"

[42] At paragraph 11.1 of Bennion, Bailey and Norbury on Statutory Interpretation (8th edition) it is suggested that the primary indication of legislative intention is the legislative text, read in context and having regard to its purpose. The issue in this case is what is meant by the phrase "death in consequence of the disease can reasonably be expected within six months". Having regard to some of the comments

made in the discussion about policy it is important to note that the test is not whether death is probable within six months; nor is it that death can be expected within six months. The use of the adverb "reasonably" introduces the concept of a range of values rather than a precise figure.

[43] Secondly, the phrase is governed by the need to identify a progressive illness. It involves an exercise in prognosis in respect of such illness. There is no dispute that the precision with which a prognosis estimating the duration of life may be made in respect of such illnesses varies widely. In some cancers it may be possible to identify a relatively narrow range within which death will occur. In cases of MND the evidence indicates that it is impossible to be precise. The consultant in the respondent's case suggested a life expectancy period of 3-5 years but even that was qualified.

[44] Thirdly, it is implicit in the provision that those facing the last six months of life with a progressive illness are highly likely to require the support which these benefits provide. Unless some fast-track to the benefits is provided, people in the last six months of life as a consequence of a progressive illness are likely to lose out on that support as a result of the bureaucratic process. That is the context within which the interpretation of this provision arises.

[45] Turning then to the practical application of the guides to interpretation it is clear that in any case where the prognosis can be fairly precisely determined a prognosis that death as a consequence of a progressive illness can reasonably be expected within six months falls within the legislative test whereas a prognosis that the time frame within which death may reasonably be expected was 9 to 12 months lies outside the SRTI.

[46] Where, however, the prognosis is more uncertain the conclusion may be that death may reasonably be expected over the next 3-12 months. Applying a grammatical construction of the qualifying condition it is clear that death can be reasonably expected within the statutory timeframe. Although death may not be probable within the 6 month period, entitlement to the benefit would, therefore, be established. The context of the provision envisages a limited period of entitlement arising from a SRTI award. That is relevant to the continuation of the payment of the benefit. In practice that review takes place after 3 years. The arrangements for review of the payment of the benefit provide an obvious protection for the public purse but do not call into question the entitlement to avail of the special rules.

[47] We accept that in cases of MND and other progressive illnesses defining even a span of time within which death can reasonably be expected is likely to be difficult but we consider that the statutory test is appropriately satisfied by asking the question whether death as a consequence of the progressive illness within a six month period would be a surprise as recommended by the DfC. In order to address the concerns noted by the APPG on Terminal Illness about the understanding of the

test by the clinicians dealing with it we suggest that this question should be incorporated into the DS1500 form as an aid to those providing an opinion.

Article 14 ECHR

[48] There are a number of helpful Supreme Court decisions giving guidance to the approach to Article 14 in the context of welfare benefits. The threads of these cases have been drawn together and been somewhat modified by the recent decision of the Supreme Court in R (on the Application of SC, CB and 8 children) v Secretary Of State for Work and Pensions and others [2021] UKSC 26 ("SC"). It is with that decision in mind that we approach the issues in this case. We acknowledge, of course, that this important authority was not available to the learned trial judge. Both parties were afforded an opportunity to make post hearing written submissions to this court.

[49] Article 14 provides:

> "The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status."

This article can only be considered in conjunction with one or more of the substantive rights and freedoms set forth in the Convention or its protocols insofar as given effect by the Human Rights Act 1998. In this case the benefits at issue are designed to support the private life of the respondent and in the case of UC her family life and plainly fall within Article 8 of the Convention on that basis. The test under A1P1 is whether but for the condition of entitlement about which the person complains he or she would have a right enforceable under domestic law to receive the benefit in question (Stec v UK (2005) 41 EHRR SE18 paragraph 54). There is no dispute that this test is also plainly satisfied and that the claim falls within the ambit of both provisions.

[50] In SC at paragraph 37 Lord Reed set out the approach adopted to Article 14 by the European Court of Human Rights ("ECtHR") which he derived from Carson v UK (2010) 51 EHRR 13 at paragraph 61:

> "(1) The court has established in its case law that only differences in treatment based on an identifiable characteristic, or 'status', are capable of amounting to discrimination within the meaning of article 14.

(2) Moreover, in order for an issue to arise under article 14 there must be a difference in the treatment of persons in analogous, or relevantly similar, situations.

(3) Such a difference of treatment is discriminatory if it has no objective and reasonable justification; in other words, if it does not pursue a legitimate aim or if there is not a reasonable relationship of proportionality between the means employed and the aim sought to be realised.

(4) The contracting state enjoys a margin of appreciation in assessing whether and to what extent differences in otherwise similar situations justify a different treatment. The scope of this margin will vary according to the circumstances, the subject matter and the background."

Status

[51] The issue of status was considered by Lord Reed at paragraph 71:

> "the issue of "status" is one which rarely troubles the European court. In the context of article 14, "status" merely refers to the ground of the difference in treatment between one person and another. Since the court adopts a stricter approach to some grounds of differential treatment than others when considering the issue of justification, as explained below, it refers specifically in its judgments to certain grounds, such as sex, nationality and ethnic origin, which lead to its applying a strict standard of review. But in cases which are not concerned with so-called "suspect" grounds, it often makes no reference to status, but proceeds directly to a consideration of whether the persons in question are in relevantly similar situations, and whether the difference in treatment is justified. As it stated in *Clift v United Kingdom*, para 60, "the general purpose of article 14 is to ensure that where a state provides for rights falling within the ambit of the Convention which go beyond the minimum guarantees set out therein, those supplementary rights are applied fairly and consistently to all those within its jurisdiction unless a difference of treatment is objectively justified". Consistently with that purpose, it added at para 61 that "while … there may be circumstances in which it is not appropriate to categorise an impugned difference of treatment as one made between groups of people, any

> exception to the protection offered by article 14 of the Convention should be narrowly construed." Accordingly, cases where the court has found the "status" requirement not to be satisfied are few and far between."

[52] The trial judge reached his conclusion on the issue of status at paragraph 97. He concluded that during the application process the respondent was a person suffering from a progressive illness as a consequence of which death was not reasonably expected within a period of six months. That is plainly an identifiable group of those suffering from a progressive illness defined by reference to the characteristic of the prognosis of that medical condition. Thus we agree that the requirement of status is satisfied.

[53] There are certain aspects of the definition of the status that should be noted. First, the statute does not provide that the opinion of a medical practitioner is conclusive. In most cases, however, a DS1500 form is provided by a medical practitioner and where the practitioner finds that the claimant has satisfied the test set out at paragraph 46 above there would have to be good reason not to accept that prognosis. Secondly, there is plainly an element of judgement involved in making the prognosis. That means that there may well be some cases where death in consequence of the progressive illness does occur within the six month period.

[54] The respondent contended before the judge that her status derived from the fact that she was suffering from a progressive illness with an unpredictable prognosis or trajectory which in all likelihood would claim her life well before she would otherwise have died. We accept that the evidence establishes that those suffering from MND have a trajectory about which it is impossible to be precise. That lack of precision feeds into the outcome of the test set out at paragraph 46 above. Some people with MND will satisfy that test and some will not. That is apparent from the figures demonstrating that one in four of the people suffering from MND receiving these benefits at present in this jurisdiction successfully claimed them under the SRTI. The difference in treatment is not based on the nature of the illness but on the prognosis and there was no evidence in this case that death was reasonably expected as a consequence of the illness within a period of six months at the time of application. We agree with the learned trial judge that the status for which the respondent argued was not one on the basis of which the respondent suffered a difference in treatment.

Analogous Position and Justification

[55] The group entitled to the benefit of the SRTI comprises those who satisfy the test at paragraph 46 above. Some of that group will die as a result of the illness within six months but many will survive for longer periods. The trial judge noted that the evidence indicated that 14% of those who were awarded the benefits on the basis of the SRTI were still receiving those benefits three years later. That is entirely unsurprising since in the case of many progressive illnesses the timeframe within

which death may reasonably be expected may be quite broad. That was certainly the thrust of the evidence before the APPG.

[56] In seeking to identify the analogous group the trial judge distinguished between those persons who satisfied the SRTI test and died within six months as a result of the illness and those who satisfied the test but survived beyond that period. In our view it is not necessary to make that distinction. It follows from our analysis of the test that many of those who benefit from the SRTI will survive, sometimes for considerable periods, beyond the six-month timeframe. That is sufficient to establish that the group of persons suffering from a progressive illness where there is a reasonable expectation of death as a result of the illness within a period of years is in an analogous position to the test group. The real issue here is justification for the difference of treatment between those groups.

[57] PIP is a non-means-tested, non-taxable cash benefit paid regardless of the individual's employment status. The assessment is based on assessing a person's needs against a range of 12 daily living and mobility activities which are central to living an independent life. Payments are either at the standard or enhanced rate depending upon the assessment.

[58] UC replaced a number of legacy benefits such as child tax credit, housing benefit and income support as well as other employment related allowances. It consists of a standard allowance plus additional elements depending on individual circumstances in respect of housing, children, caring responsibilities, childcare costs, responsibility for disabled children and health and disability related needs.

[59] Both benefits are plainly related to capacity and need and are independent of any particular diagnosis. There is an assessment process which ensures that an applicant can make the case for their requirements to be taken into consideration and for the payment of an appropriate amount for those.

[60] The definition of "terminally ill" was introduced into legislation in 1990. The key objective behind the provision was to provide those defined as "terminally ill" with immediate access to the benefit by exempting them from the initial six month qualifying condition because individuals were dying before the entitlement had been determined. The review in 2010 by SSAC indicated general satisfaction with this approach although the MND Association had argued for an extended period of 12 months.

[61] In order to determine justification the first step is to establish that the measure has a legitimate aim. We do not understand that there is any significant dispute that the objective identified in 1990 remains appropriate and the trial judge noted at paragraph 72 the rationale set out in the affidavit of Ms Parker:

> "the current rules provide a clear and specific definition of terminal illness which ensures that those closest to

> death are given immediate access to PIP and the LCWRA element of UC. The definition safeguards public funds by avoiding an open ended definition which would apply to vastly more people than currently qualify, whilst also providing a clear threshold against which the medical practitioners can assess claimants. The rules have operated well in practice and have not, until recently, led to significant pressure for reform."

[62] There are 4 propositions which one can derive from this statement:

(a) people close to death as a result of a progressive illness are likely to satisfy the conditions for the award of these benefits;

(b) such people should have a fast track means of accessing those benefits;

(c) it is necessary to set a threshold for the identification of that group in order to protect public funds; and

(d) the definition of terminal illness is sufficiently clear and specific to enable medical practitioners to identify that threshold.

[63] We accept that there has been a measure of uncertainty about the definition of terminal illness but in light of our conclusions at paragraph 46 above we consider that the definition can be said to be clear and specific. We are also satisfied that the definition ensures that a group of people who are closest to death are given immediate access to the benefits. That is the legitimate aim. We accept that the definition safeguards public funds. Although some medical practitioners have had difficulties assessing claimants against the test the evidence indicates that the rules have operated well in practice and have not until recently led to significant pressure for reform.

[64] The next question is what has to be justified in this particular context. In his analysis of the issue of justification the learned trial judge at paragraph 102 of his judgment explained that what had to be justified was not the measure in issue but the difference in treatment between one person or group and another. He then compared the position of the respondent with a person who had satisfied the SRTI test but lived for a period in excess of six months.

[65] Considerable assistance on this issue is found at paragraph 125 of SC:

> "The cases of *Stec, Zeman, Runkee, Andrle, Luczak, Andrejeva, British Gurkha* and *Tomás*, all concerned with "suspect" grounds of differential treatment, might be contrasted with others concerned with non-suspect grounds. The case of *Carson* (2010) 51 EHRR 13 concerned

> the differential treatment of recipients of the state pension depending on whether they were resident in the United Kingdom or overseas. Unlike sex and nationality, residence is not one of the so-called suspect grounds. The Grand Chamber's approach reflected that difference. It repeated at para 61 what had been said in *Stec* (para 118 above) about a wide margin, and respecting the legislature's policy choice unless it was "manifestly without reasonable foundation". It made no reference to "very weighty reasons". It also underlined that, in the context of welfare benefits and pensions, it will look at the compatibility of the system overall, without giving undue weight to the circumstances of the individual, since welfare systems, to be workable, have to deal in broad categorisations which will inevitably affect some people more prejudicially than others."

This is a case involving welfare benefits and it is the compatibility of the system overall that has to be justified.

[66] The learned trial judge applied the "manifestly without reasonable foundation" test. Lord Reed carried out a detailed examination of the relevant European and domestic authorities between paragraphs [97]-[162] of SC. His conclusions are set out at paragraph [161] and [162]:

> "161. It follows that in domestic cases, rather than trying to arrive at a precise definition of the ambit of the "manifestly without reasonable foundation" formulation, it is more fruitful to focus on the question whether a wide margin of judgment is appropriate in the light of the circumstances of the case. The ordinary approach to proportionality gives appropriate weight to the judgment of the primary decision-maker: a degree of weight which will normally be substantial in fields such as economic and social policy, national security, penal policy, and matters raising sensitive moral or ethical issues. It follows, as the Court of Appeal noted in *R (Joint Council for the Welfare of Immigrants) v Secretary of State for the Home Department (National Residential Landlords Association intervening)* [2020] EWCA Civ 542; [2021] 1 WLR 1151 and *R (Delve) v Secretary of State for Work and Pensions* [2020] EWCA Civ 1199; [2021] ICR 236, that the ordinary approach to proportionality will accord the same margin to the decision-maker as the "manifestly without reasonable foundation" formulation in circumstances where a particularly wide margin is appropriate.

> 162. It is also important to bear in mind that almost any legislation is capable of challenge under article 14. Judges Pejchal and Wojtyczek observed in their partly dissenting opinion in *JD*, para 11:
>
> > 'Any legislation will differentiate. It differentiates by identifying certain classes of persons, while failing to differentiate within these or other classes of persons. The art of legislation is the art of wise differentiation. Therefore any legislation may be contested from the viewpoint of the principles of equality and non-discrimination and such cases have become more and more frequent in the courts.'
>
> In practice, challenges to legislation on the ground of discrimination have become increasingly common in the United Kingdom. They are usually brought by campaigning organisations which lobbied unsuccessfully against the measure when it was being considered in Parliament, and then act as solicitors for persons affected by the legislation, or otherwise support legal challenges brought in their names, as a means of continuing their campaign. The favoured ground of challenge is usually article 14, because it is so easy to establish differential treatment of some category of persons, especially if the concept of indirect discrimination is given a wide scope. Since the principle of proportionality confers on the courts a very broad discretionary power, such cases present a risk of undue interference by the courts in the sphere of political choices. That risk can only be avoided if the courts apply the principle in a manner which respects the boundaries between legality and the political process. As Judges Pejchal and Wojtyczek commented (ibid):
>
> > 'Judicial independence is accepted only if the judiciary refrains from interfering with political processes. If the judicial power is to be independent, the judicial and political spheres have to remain separated.'"

[67] In this case the difference in treatment concerns the means of access to a set of benefits where those who suffer from a progressive illness as a consequence of which death can reasonably be expected within six months are fast tracked through

to the benefit whereas those in respect of whom death cannot reasonably be expected within six months must go through the application process. It is, therefore, a case about whether or where to draw the line within the welfare system.

[68] Secondly, this is an area in which there has been parliamentary consideration in 1990 and 2010. The evidence indicates that the system was judged to have operated well in practice until recently. DWP commenced a review consequent upon the APPG report in July 2019. A stakeholder workshop was held by DWP in London in late October 2019 and a similar event was held by DfC in Northern Ireland in December 2019. These proceedings were issued on 6 December 2019 some months after the process of review commenced. The DfC Minister has indicated an intention to extend the timeframe to 12 months which is that for which the MND Association argued in 2010.

[69] Thirdly, there is no dispute about the fact that some special provision was necessary in relation to those who might die as a result of a progressive illness in the course of going through the application process. The benefits in question are needs based. The line has been drawn at a point which seeks to identify that group of people suffering from a progressive illness where the need is highly likely to have arisen.

[70] Fourthly, the extension of the SRTI to those who have a diagnosis of a progressive illness as a consequence of which death can reasonably be expected would change the basis for the award of the benefit. It would no longer be needs based. It would be determined by the diagnosis of a particular condition independently of need.

[71] Fifthly, we accept that there is an element of professional judgement involved in the determination of the prognosis by a medical professional. There is, however, no dispute about the importance of clinical judgement in this area and indeed it is part of the respondent's case that clinical judgement should determine the award of the benefit. We recognise, therefore, that the test is not hard edged and there may be some element of inconsistency but in order to achieve the aims of ensuring the availability of a fast-track for those who need it and safeguarding public funds we accept that clinical judgement is an adequate and acceptable tool.

[72] Sixthly, we accept that one of the options available to policy makers is to provide that clinical judgement should make the determination of need in cases of progressive illness. That would involve consideration of the robustness of compliance with the needs based approach, the risk of diagnostic variability and any impact on budget. This court is not in a position to make an assessment of those matters.

[73] The respondent introduced a Thlimmenos argument on appeal contending that the respondent should have been treated differently from other applicants for the benefits who did not qualify under the fast-track approach. The difference

between the respondent and other applicants is that she has a diagnosis of a progressive illness. The award of the benefit is not dependent upon the nature of the illness. It is dependent upon need. A change in the access arrangements of the SRTI to facilitate particular medical conditions would represent a departure from the needs basis of the present provisions. That is plainly a controversial political matter which it is not for the courts to determine.

[74] In this area of welfare benefits substantial weight is generally accorded to the primary decision maker. We do not accept that this is a case in which the difference of treatment is based on a suspect ground such as sex or religion. We accept that a relatively strict approach has been taken in cases concerned with persons with disabilities in order to foster their full participation and integration in society. That objective is honoured in this case by the application process based on need. This is not a case where the applicant has been excluded from the benefit.

[75] The legislature has been involved in a detailed consideration of where to draw the line in this welfare benefit in 1990 and 2010. There has been continuing review of that decision since 2018. The Minister intends to submit a further proposed amendment to the Northern Ireland Assembly which will provide an opportunity for debate and reflection by the legislature. This is an area where considerable weight should be given to the views of the primary decision maker. These choices are for the political process and not for the courts.

Conclusion

[76] For the reasons given the appeal is allowed and the cross-appeal must be dismissed.