All Party Parliamentary Group
for Terminal Illness

Written evidence: The legal definition of terminal illness

February – May 2019

Contents

Professionals

1. Timothy L Williams, PhD, FRCP, Newcastle MND Care Centre Director

I am of the opinion that the definition or use of the figure of 6 months should not be scrapped completely.

I think a slight loosening to 6-12 months at the discretion of the clinician is better and fairer, but to remove any control of this by timescale is ludicrous in my opinion.

I have been an specialist in MND management and MND care centre director in Newcastle since July 2000.

2. Dr Steve Marshall PhD, MA, BA (Hons), PGDipSW, Research Associate, King's College London

Unfortunately we have little evidence beyond the anecdotal, as we have never collected any data around the DS1500s issued by our clinical team. We issue approx. 100 each year, and my feeling is that our team is more likely to issue a DS1500 for younger, working age patients and people with more predictable conditions such as cancer. I suspect that non-malignancies such as COPD and heart failure, where it can be much more difficult to estimate prognosis, are less likely to be considered appropriate for a DS1500. However I have no evidence to support this.

The terminology of terminal illness and a prognosis of 6 months does not sit well with me either - we would normally associate terminal with end-of-life care. Many of our patients would be considered to have a prognosis of 6 months or less, but we would not consider them to be in the 'terminal' phase of their illness. Perhaps the term life-limiting condition would be more appropriate, and more clinicians would then consider a patient appropriate for a DS1500?

I hope my comments are helpful. I would be happy to discuss this with you further, and would also be happy to be involved in any further projects around this issue.

3. Anne-Marie Raftery, Clinical Lead & Macmillan Clinical Nurse Specialist in Palliative Care, Pathway Director-Palliative Care, Greater Manchester

As a professional who regularly deals with DS1500 applications for patients with cancer, I would like to comment on the legal definition of terminal illness inquiry for the purpose of accessing fast-track welfare benefits.

I feel that the definition does not reflect the reality of living with a terminal illness such as cancer and that the 6 month rule is restrictive, as professionals feel they need to be 100% accurate in their predictions of life expectancy.

I would suggest that the 6 month rule be replaced with the clinical judgement of a professional, which should not be restricted to a medic as senior nurses and other AHP’s are also well equipped, without an arbitrary time limit.

4. Dr Clare Gardiner, Senior Research Fellow, The University of Sheffield, School of Nursing

Dr Gardiner is a Senior Research Fellow at the School of Nursing and Midwifery at The University of Sheffield, where she works as part of the multi-disciplinary Palliative and End of Life Care research group. She has been involved in palliative and end of life care research for over 10 years, and has published over 60 academic papers in peer review journals. She has been involved in a number of national and international research projects, totalling over £3 million of funding to date. She currently holds a Vice Chancellors Fellowship to explore the financial costs of informal caregiving for people at the end of life.

<u>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?</u>

The main problem with this definition is not the timescale of six months, but the difficulty that is inherent in trying to identify which patients are likely to die within a specified time period. For patients with cancer, it is relatively easy to prognosticate and to predict when someone is within six months of death. However, for patients dying from non-cancer conditions (in particular organ failure, neurological conditions and dementia/frailty) it is incredibly difficult to predict with any degree of accuracy how long someone has left to live. For example, in our study of patients with Chronic Obstructive Pulmonary Disease (COPD) GPs exhibited large variations in prognostication for patients with similar clinical profiles (Small 2010). A recent systematic review explored the accuracy of the question “would you be surprised if this patient were to die in the next 6 months”. This study identified wide variation in the accuracy of doctors predicting death, and indicated that the accuracy is worst for non-cancer conditions (White 2017). This suggests that whilst the definition of terminal illness may be appropriate for cancer patients, it unfairly disadvantages those patients with less predictable disease trajectories. Patients with non-cancer conditions have a high symptom burden towards the end of life, comparable to cancer, yet these patients are not able to access the same financial support as cancer patients.

<u>Does the six month definition help or hinder people affected by terminal illness to receive the support that they need?</u>

The definition of terminal illness acts to the detriment of patients with unpredictable disease trajectories. This includes patients with organ failure, neurological conditions including MND and those with advanced frailty and/or dementia. Recent research from our group indicates considerable inequity in the availability of financial support towards the end of life (Gardiner, in press). In particular, patients with non-cancer conditions appear disadvantaged because they are usually not eligible for the SRTI, due to the issues identified above with unpredictable disease trajectories.

5. Anne Marie Marley, Respiratory Nurse Consultant, Belfast Health and Social Care Trust

As an integrated respiratory specialist team we collectively feel the 6 months rule for terminal illness is no longer fit for purpose. We place great priority on delivering palliative care to our non-malignant respiratory patients. The majority have conditions such as COPD, Interstitial Lung Disease and end stage bronchiectasis. At the present minute we have over 250 patients on our community caseload whom we deem to have palliative and end of life care needs. Any of these patients could pass away if hit by a serious chest infection or flare up of their condition but for whatever reason, hopefully co-ordinated integrated care the patients may live for longer. It is possibly this uncertainty that hinders people in the definition of terminal illness.

We use the Gold Standard prognostic indicators, the number of hospital admissions, the ‘surprise question’ (ie would you be surprised if your patient died within 6-12 months), the use of non-invasive ventilation and long term oxygen therapy, whether they are housebound and their ability to complete activities of daily living as a guide to decide if the patients has palliative care needs. Often this is compound by high levels of anxiety and depression, lethargy and isolation.

The patients is then discussed as part of a multidisciplinary meeting so the health professional, usually the experienced Respiratory Nurse Specialist, so no-one is making the clinical assumption on their own. A palliative care plan is then discussed.

The definition and language can be a barrier with many having different interpretations of what terminal illness actually is especially when the diagnosis does not relate to cancer. Often they are considered to be chronic long term conditions and the transition or deterioration in a person’s condition is hard to identify.

We now also have very complex interventions which can keep patient alive despite life threatening flare ups of their condition but this does not negate the fact that their underlying condition is still in a terminal, end of life stage, such as non-invasive ventilation.

In NI we also have the End of Life Care Operational System which outlines what health professionals should be doing at each stage of the process.

Again the 6 month definition also hinders the person from accessing these benefits. The issues arise when professionals are anxious about discussing these end of life issues with patients because prognostication can be so difficult. At times the patients are not referred for the DS1500 because the clinician does not want to raise the difficult subject because of this difficulty. When these conversations are had with the patient and/or family member it will be based on a thorough assessment of need so does not warrant the distress for the patient of having to have a reassessment done by an assessor from PIP who will be working on their own and without the clinical skill and expert knowledge of the health professional.

These are benefits which can make a very real difference to people with end of life respiratory illness.

Organisations

6. Citizens Advice

About Citizens Advice

Citizens Advice provides free, confidential and independent advice to help people overcome their problems. Over the last 12 months (up to the end of March 2019) we have helped over 570,000 people with almost 1.4 million benefits issues.

Over the last 18 months we have also published several reports on benefits based on our client data, insights from frontline advisers, and interviews with clients. Citizens Advice has a network of 280 local offices. Last year, our advisers submitted around 11,000 case studies detailing the experiences of the some of the people they helped. This information helps us understand how the benefits system is working for claimants. Advisers helped people with over 8,400 ‘special rules’ for benefit issues last year. These rules for terminal illness allow people who are issued a DS1500 form their doctor to have access to benefits fast tracked. Where people are eligible, It is one of the areas where we frequently receive positive reports from advisers. Many people we help meet the 6-month definition, are able to get their doctor to sign a DS1500, and tell us they encounter decision makers who apply the special rules correctly. This makes it easier for terminally ill individuals to access support smoothly - at a moment in life where they often do not have the time or capacity to go through the standard process of claiming benefits.

Terminally ill client in the South East gets vital, backdated support because of an “exceptionally helpful” decision maker.

A DWP decision maker was exceptionally helpful with a PIP award for a person who had been making a claim on the basis of a terminal illness before being issued a DS1500. The decision maker not only fast tracked the claim, but helped facilitate the backdating of payments since the client had been terminally ill before his claim or issuance of the DS1500. The award was backdated to 6 weeks before date of claim.

However, some people we see do still face administrative problems even when they qualify for special rules. We have seen some cases of individual decision makers not assessing claimants correctly for eligibility for special rules. We have also seen cases where the rules have not been applied across different benefits.

Problems falling outside the definition

Not all terminally ill people are eligible for a DS1500, either because they fall outside of the 6-month definition, or they are unable to get their doctor to fill the DS1500 form out.

Without a DS1500, these individuals will have to go through the standard application process for benefits, which can often be stressful and complicated. Some of the difficulties we hear from our clients include confusion about the system, problems evidencing claims, and issues with inaccurate assessments. In practice, this means that people with a terminal illness who do not have a DS1500 may spend significant periods of time applying for benefits. If people wish to challenge a decision on their benefit claim, they can face weeks going through the Mandatory Reconsideration process1, as well as the appeals process if deemed necessary. Similar to other claimants, this can leave people waiting a long time for much-needed financial support through benefits, without any guarantee that they will be successful.

Terminally ill mother in London experiences familiar problems with Universal Credit

A single mother whose cancer returned after 4 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.

The definition has caused particular problems for some people we help who made benefit claims prior to qualifying or becoming aware of the special rules. For these clients, Citizens Advice see problems reporting changes of circumstances or accessing the special rules. Others become eligible for, or aware of, a DS1500 at a late stage in their illness, and having already been through negative experiences making benefit claims are put off applying.

DS1500 wrongly interpreted as evidence in a Mandatory Reconsideration

One person Citizens Advice helped in the South of England was diagnosed with cancer. Her family made an application for PIP, which 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 6-month definition has meant the special rules fell in the middle of a terminal diagnosis. Though she was ultimately backdated her PIP, it meant stress and uncertainty while waiting several of her remaining weeks for an award to be confirmed and a payment to be made.

Recommendations

Eligibility for a DS1500 is a lifeline for the terminally ill people who qualify. It allows them to fast track applications and circumvent systems that can otherwise take weeks. It can be difficult and time consuming for many terminally ill people who do not meet the 6-month definition with special rules to access the support they need. The Government should address problems for terminally ill people through two tracks:

● Review the 6-month definition to provide greater scope to include people who have more than 6 months to live but who have a progressive illness that is likely to lead to them dying.

● Under any definition there will always be some people who are not eligible, or are unable for some reason to access the special rules. Therefore, alongside changes to the definition of terminal illness, the Government must continue to improve the benefits system to ensure that people are able to access financial support they are entitled to quickly and simply.

7. Advice Northern Ireland

Background

Advice NI is a membership organisation that exists to provide leadership, representation and support for independent advice organisations to facilitate the delivery of high quality, sustainable advice services. Advice NI exists to provide its members with the capacity and tools to ensure effective advice services delivery. This includes: advice and information management systems, funding and planning, quality assurance support, NVQs in advice and guidance, social policy co-ordination and ICT development.

Membership of Advice NI is normally for organisations that provide significant advice and information services to the public. Advice NI has over 70 member organisations operating throughout Northern Ireland and providing information and advocacy services to over 110,000 people each year dealing with almost 250,000 enquiries on an extensive range of matters including: social security, housing, debt, consumer and employment issues. For further information, please visit www.adviceni.net.

Introduction

Benefits like PIP, Universal Credit and ESA have Special Rules for claimants who have been diagnosed with terminal illnesses, which allows them to get faster access to the payments they are entitled to, without having to fill in as many lengthy forms, go through face-to-face assessments or, in the case of Universal Credit and ESA, attend sessions with job coaches. The Special Rules process means that people can access the support they need quickly, with as little bureaucratic interference as possible – allowing them to enjoy a better quality of life during the time they have left

The problem is that only people who have a medical prognosis of six months or less to live are eligible to apply for benefits under these Special Rules. This is excluding many legitimate claimants with unpredictable conditions like motor neurone disease, chronic heart failure and others, for which it is incredibly difficult for medical professionals to give an accurate estimation of life expectancy.

These claimants have to apply for support through the normal rules, which involves a lengthy and complicated application process and, for some benefits, may result in them having to meet work requirements in order to continue receiving their payments. This is unfair, undignified and needs to change.

Advice NI wants to remove this arbitrary six month criterion and replace it with a new system based on clinical judgement instead, as has been adopted in Scotland. In Northern Ireland, a recommendation to remove the six month life expectancy criterion for terminally ill PIP applicants was included in Walter Rader's independent review of the PIP assessment process in 2018. However, the lack of a Stormont Assembly has meant that the Department for Communities is unable to change the rules.

Scope of the problem

To use an arbitrary time period of 6 months as a 'guarantee' or 'proof' of terminal illness is out-dated, and arguably increases the stress on claimants and their families. That 6 months is unsuitable is suggested by a variety of sources, including the Rader report, Recommendation 6:

That the clinical judgment of a medical practitioner, indicating that the claimant has a terminal illness, should be sufficient to allow special rules to apply. The 6 months life expectancy criterion should be removed.

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 judgment indicating a terminal condition. This should be sufficient to allow for special rules to be applied .

The Scottish Government states the following:

Terminal illness is a complex and sensitive clinical issue. A terminal illness is regarded as a progressive disease, which can reasonably be expected to cause an individual's death. Terminal illness includes a wide range of different diseases and individuals may have a single disease or a number of conditions at any one time.

Following further consultation, an amendment was lodged and unanimously approved by the Parliament on 25 April 2018, which will ensure that the definition of terminal illness for the purpose of disability assistance, will be based on the clinical judgement of a registered medical professional, removing any reference to a time-restriction.

The MND Association said it agreed the UK government should follow Scotland's example:

Scotland voted to remove the six month rule and replace it with a clinical judgment. This means that doctors and consultants who know their patients and understand their conditions *can make a judgment about whether they are terminally ill, without worrying about an arbitrary six month requirement.*

Medical professionals who support the view that a 6-month time limit is untenable; in April 19th, 2018, 50 doctors wrote an open letter to the Times, stating

Six months life expectancy has no clinical meaning in most terminal illnesses, because there is no clearly defined disease trajectory

It's vital that this six month limit is scrapped, as it has a profound impact on virtually all aspects of care for people with MND." – consultant neurologist Nikhal Sharma.

Marie Curie clearly states that terminal illness, while having the same ultimate outcome for patients, is not a uniform, time-bound condition:

Depending on their condition and treatment, people may live with a terminal illness for days, weeks, months or even years.

Daphne Hall, Vice Chair of National Association of Welfare Rights Advisers stated that issues with the current system include:

Medical professionals not fully understanding the phrase 'death could reasonably be expected within six months' and deciding that a DS1500 is not appropriate

Rigidity of specifying six months which is difficult to align with current treatments which may offer the opportunity of giving a few extra months to someone with a terminal illness

Disagreement between professionals about whether a DS1500 should be provided…

NAWRA strongly believes that the government should follow the Scottish approach thereby ensuring that people in the last stages of their lives receive the benefit they need as quickly and easily as possible.

I would suggest that the 6 month criteria is not fit for purpose. 6 months is an arbitrary period of time. In some instances the person may in actuality live well beyond the 6 months, in other cases they sadly will not live even that long. It is really best guess. This will depend on the medical professional's experience, their seniority, how familiar they are with the patient or their records, and their willingness to be both realistic and frank about the prognosis in question.

When I have discussed this with medical professionals to try and encourage the completion of DS1500s where appropriate, it has been clear to me that there is a generalised fear of making a mistake and being pulled up on it i.e. signing the DS1500 and then the patient lives for a year.

In other cases they may be aware that they are terminally ill or receiving palliative care, but have requested not to be informed of the expected time frame. This is their right but in such *cases, they may not be in a position to request a Special Claims claim, unless they are dealing with a specialist adviser who is able to navigate this complex area. In this way, the 6 month criteria is very much a barrier to the patient receiving the support they need.* Nuala Harraghy, Macmillan Benefits Service

Advice NI Recommendation

This argument to amend this 6-month rule is not just being proposed by the claimants, or the third sector, but is championed by mental health experts from national charities, as well as being passed into legislation by one of the countries in the U.K. [Scotland]. There has not been a sudden influx of terminally ill people claiming PIP following this ruling. There is strong supporting evidence from medical professionals that the current 6 month rule is not fit for purpose. At such a difficult and sensitive time for the claimant and their families, the 6 month rule adds an unnecessary layer of bureaucracy.

Cost may be a concern for the government. Overall, UC will cut benefit spending by £2.7 billion a year in the long run , according to the Institute for Fiscal Studies. Therefore any additional cost necessitated by this policy change could easily be covered by the savings that the Government will make, following the introduction of Universal Credit.

8. Law Centre NI

Law Centre (NI) welcomes this opportunity to respond to the All-Party Parliamentary Group for Terminal Illness Inquiry into the legal definition of terminal illness. This issue was highlighted to us by a leading cancer charity in Northern Ireland who contacted the Law Centre (NI) through our social security advice line.

Law Centre (NI) promotes social justice and provides specialist legal services to advice organisations and disadvantaged individuals in social security, community care, immigration and employment law. Law Centre (NI) convenes regular Adviser Network Meetings across NI for welfare rights advisers and convenes the Welfare Reform Group, which is an umbrella grouping of organisations that campaign for positive changes to policy, service provision and legislation for persons in receipt of social security. As co-convenors of the Cliff Edge NI Coalition, we are working in partnership with over 65 organisations concerned about the cessation of the current welfare reform mitigations in Northern Ireland.

Law Centre (NI) has addressed the issue of the application of the current criterion through its advice line. The current definition of terminal illness (‘the 6 month criterion) raises the following issues:

- the potentially detrimental impact on the mental health of terminally ill claimants.
- that the effect of the six month criterion is that benefits are refused to individuals with a terminal illness who cannot establish this criterion with reasonable certainty as a result of the unpredictable trajectory of their condition, albeit that death may occur within 6 months.

Consideration of the Six Month Criterion in NI

The Independent Review of PIP, carried out by Walter Rader on behalf of the Department for Communities (‘DfC’) concluded that the six month criterion was unfit for purpose. In June 2018, the Review noted:

That the clinical judgment of a medical practitioner, indicating that the claimant has a terminal illness, should be sufficient to allow special rules to apply. The 6 months life expectancy criterion should be removed.

Also in June 2018, representatives from six political parties in NI (SDLP, DUP, SF, UUP, Alliance and Green Party) wrote a joint letter to the Permanent Secretary of the Department asking that a working group be established with the DfC to begin the preparatory work required, including an analysis of the implications, of the introduction of a definition of terminal illness based on clinical need, rather than any time-restricted understanding of life expectancy.

In November 2018, DfC provided an interim response to the Rader Review, indicating that:

Under the statutory framework provided for in the Northern Ireland Act 1998 social security law in Northern Ireland is maintained in parity with provision brought forward by DWP in Great Britain, unless the Executive and Assembly determine otherwise. While the Department acknowledge the opinion of the reviewer, it will be of incoming Ministers to determine if they wish to initiate any review of current arrangements

According to DfC policy, if someone is awarded PIP as a result of terminal illness there is no review of the award within 3 years. There is a clear conflict present in this process in that someone cannot qualify unless death is expected within 6 months but there is an acknowledgment that survival may exceed 6 months and therefore no review should be carried out within 3 years.

In Scotland consideration of this issue resulted in the removal of the 6 month requirement from the definition of terminal illness. Pursuant to its devolved powers, the Scottish Parliament recently passed the Social Security (Scotland) Act 2018. Schedule 5 paragraph 1 requires that regulations on eligibility for disability assistance adopt a definition of ‘terminal illness’ which is based on the judgment of a registered medical practitioner. This provision appears to be in line with the recommendation made by the Rader Review.

The Impact of the Six Month Criterion on Terminally Ill Claimants

The six month criterion hinders the ability of people affected by terminal illness to receive the support that they need.

Some claimants have expressed concern that by making an application and relying on a DS1500 in order to receive the enhanced rate of PIP will indicate that they have psychologically “given up”. The following case study, featured on BBC NI in autumn 2018, underscores concerns of the potentially negative impact on claimants.

A claimant in NI was diagnosed with cancer and, after receiving the Disability Living Allowance (DLA) for a period, she was notified that she would have to be reassessed for PIP. She refused to get the DS1500 signed, saying that complying with this “degrading” requirement would be like "signing her death warrant".

The effect of the six month criterion is that benefits are payable to individuals with a terminal illness who can establish with reasonable certainty that death can be expected within 6 months; but benefit is refused to individuals with a terminal illness who cannot establish this criterion with reasonable certainty as a result of the unpredictable trajectory of their condition, albeit that death may occur within 6 months.

The system favours claimants with a predictable disease trajectory, such as some types of cancer. Cancer accounted for less than a third of deaths in Northern Ireland in 2016, but it represents over 90% of local PIP claims awarded under Special Rules for Terminal Illness. This suggests that a large number of people with other terminal illnesses are not accessing PIP under the Special Rules.

A claimant in NI who was diagnosed with motor neurone disease was unable to apply for PIP under the fast-track Special Rules for Terminal Illness because she doesn’t have a medical prognosis of six months or less to live. This claimant expressed her sadness that, because of the six month criterion, people with terminal illnesses are forced to spend their time fighting against an unfair system rather than being able to spend time with the people they love the most.

Marie Curie in its evidence before the Rader Review identified this particular difficulty:

For many terminal illnesses, particularly non-cancer conditions like motor neurone disease (MND), chronic heart failure, chronic obstructive pulmonary disease and dementia, accurate prognosis can be difficulty because of the unpredictable trajectories of these conditions. The rate of progression can vary, and patients may be expected to live for a longer period but die within six months due to a sudden decline in their condition.

Potential challenges to the Six Month Criterion

The six month criterion in Northern Ireland is contained in primary legislation (Article 87(4) of the Welfare Reform (NI) Order 2015). Therefore, further amending legislation would be required to remove the 6 month criterion. Law Centre NI is of the opinion that in the absence of amending legislation passed by a functioning Assembly, the legislation is still potentially open to challenge, either as a breach of the European Convention on Human Rights (‘EHCR’) or, alternatively, by virtue of the principles of Administrative Law:

In summary, there may be merit in the arguments that the imposition of the 6 month criterion and the manner in which this impacts on particular claimants, and/or those potentially eligible for the benefit, breaches Article 1 Protocol 1 and/or Article 8, ECHR, read in conjunction with Article 14, Article 1 Protocol 1 ECHR on a freestanding basis, as well as common law principles of Administrative Law.

Subject to any legal challenge to the application of the current test, Law Centre makes the following proposals for next steps in NI and urges the All Party-Parliamentary Group (‘APG’) to adopt the following recommendations.

Recommendations

Law Centre (N) recommends that the APG supports the introduction of a definition of terminal illness based on clinical need, rather than any time-restricted understanding of life expectancy and urges Westminster to review the position.

Law Centre (NI) recommends that the APG, whilst recognising the devolution arrangements, urges the DfC to progress the review by the Department of the 6 month criterion and its impact on terminally ill claimants.

Similarly, Law Centre (NI) recommends that the APG supports the call for a working group to be convened composed of the main political parties, relevant civil society organisations and the DfC to initially scope what preparatory work may be required, pending a ministerial direction to proceed. This would facilitate a timely response should ministerial direction be secured and would include preliminary analysis of implications of the introduction of a definition of terminal illness based on clinical need.

9. MND Association

The Special Rules for Terminal Illness (SRTI) application process is intended to enable claimants who are terminally ill to access disability benefits rapidly, without going through the standard application process. The SRTI application route is available for Employment and Support Allowance (ESA), Personal Independence Payment (PIP), Attendance Allowance and Universal Credit (UC).

For those who are able to access it, the SRTI process usually works well. Successful SRTI applications enable the claimant to access higher rate of benefits more quickly (including the enhanced daily living component of PIP, but not the mobility element) without waiting for any qualifying periods to come to an end, having to fill in a long form or undergo a face-to-face assessment. It also exempts people who are terminally ill from the requirement under Universal Credit for claimants to discuss their work aspirations with a work coach.

However, too many terminally ill claimants find themselves excluded from the SRTI process. This is largely due to the impact of the current legal definition of terminal illness for the purpose of accessing benefits, which hinders many terminally ill claimants from accessing the process. For this reason, the MND Association believes that the current definition is not fit for purpose, for the reasons set out below.

Impact of the legal definition of terminal illness

The primary issue with the SRTI process is its restrictive eligibility criteria, which limit access to the process and force many people living with terminal conditions to apply via the standard application process. The standard process is extremely burdensome and time-consuming for a person dealing with the devastating emotional and physical impact of a diagnosis of a terminal condition such as motor neurone disease (MND).

The eligibility rules for the SRTI process are set out in the Welfare Reform Act 2012, which states that: “a person is “terminally ill” at any time if at that time the person suffers from a progressive disease and the person’s death in consequence of that disease can reasonably be expected within 6 months.” (Welfare Reform Act 2012, Part 4).

This definition means that the SRTI process is problematic for a number of reasons:

1) The timescale is short compared to the progression of some terminal illnesses.

2) The definition does not reflect the difficulty of providing an accurate prognosis for individuals living with complex terminal illnesses.

3) Health professionals’ interpretations of the definition vary significantly, leading to inequity of access.

4) Health professionals have reported that assessors contact them to question submitted DS1500 forms.

1) The timescale is short compared to the progression of some terminal illnesses

The requirement for a “reasonable expectation” of death within six months, if strictly interpreted as a prognosis of six months or less, can exclude many people living with terminal and highly disabling conditions.

Currently, fewer than half of Personal Independence Payment (PIP) claimants with MND are able to access the SRTI process. Data from the Government’s online statistics portal, StatXplore, shows that of 1767 PIP claims currently in payment for people with MND, 791 (44.7%) were through SRTI and 979 (55.4%) were not (data extracted May 2019). Data for other disability benefits is not currently available on a condition-specific basis.

This has a damaging effect on claimants, because the SRTI process is far more suitable for people with a diagnosis of MND than the standard application process. People living with MND have to cope with a devastating diagnosis of a condition that is terminal in all cases, progresses unpredictably and often rapidly, and causes major and progressive disability. The SRTI route can provide rapid access to the vital support they urgently require, unlike the standard process, which is difficult and time-consuming to complete and in the case of PIP includes a 3-month qualifying period. It is unfair to ask some people with terminal illnesses to apply through the ‘normal rules’ because they might have a slightly longer life expectancy than others, or because it is not possible to accurately predict that they are in the last six months of life. As the vast majority of people with MND are likely to be awarded higher rates of disability support in any case due to the nature of the disease, there is nothing to be gained in forcing them down the lengthy and burdensome standard application process.

There is particular concern over the impact of exclusion from the SRTI process on Universal Credit (UC) claimants. The UC 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, will be asked to attend work-focussed interviews at a JobCentre Plus with a work coach 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 insulting to a person who has had to give up work because of a progressive and terminal illness. Claimants applying via SRTI will not be expected to undergo these procedures. However, under the current regulations the majority of claimants with MND will not be able to apply through SRTI and consequently will be exposed to highly inappropriate work coaching requirements.

2) <u>The 6-month definition does not reflect the difficulty of providing an accurate prognosis for individuals living with complex terminal illnesses</u>

Individuals with a confirmed terminal diagnosis should not be unfairly excluded from the SRTI process because they have a less predictable or less well-understood condition. The current language around SRTI eligibility wrongly assumes that life expectancy can be accurately estimated for people living with terminal illness. Research from the Marie Curie Palliative Care Research Department, University College London, examined the accuracy of over 8,000 prognostic estimates for terminally ill patients in the UK. It found that accuracy varied from 23% to 78%.

MND is a highly complex condition, and MND progression is extremely variable and difficult to predict. With our current level of understanding of MND it is not possible to give a precise prognosis of life expectancy in individual cases. There is therefore a need to allow for a sensible degree of flexibility in cases where an individual is living with an unpredictable terminal condition.

A common prognosis for a person living with MND is for a life expectancy of 1-5 years, which reflects the difficulty of providing a precise prognosis for individuals living with the condition. Around a third of people with the condition will die within one year of diagnosis and more than half within two years, while others will live with the condition for longer. As the speed of progression is very difficult to predict, MND specialists have spoken out about the impact of the SRTI criteria. In 2018, 31 specialist MND clinicians wrote a letter to the Daily Telegraph describing the criteria as ‘entirely inappropriate’ for people living with MND. In 2019, Dr Nikhil Sharma, a neurologist specialising in MND, wrote in the British Medical Journal that life expectancy is ‘often impossible to predict accurately, particularly in a condition such as MND where the prognosis is highly variable.’ (British Medical Journal, ‘Benefits for terminally ill patients’, 7th February 2019).

3) <u>Health professionals' interpretations of the definition vary significantly, leading to inequity of access</u>

As a result of the inherent unpredictability of MND described in point 2) above, professionals have a difficult judgment to make when asked to sign a DS1500 form for someone with MND. Consequently, there is variation in how the SRTI criteria are interpreted and in doctors' willingness to submit the form for people with MND. Some interpret the criteria broadly enough to submit the form on behalf of the majority of claimants with MND, while others feel that the current criteria restrict their ability to support SRTI applications in many cases. As a result, claimants' access to the SRTI process depends to a large extent on the attitude and interpretation of individual clinicians, leading to variation and inequity of access. More flexible criteria would give doctors more confidence to support SRTI claims for people with a terminal condition such as MND.

An independent poll of a thousand GPs conducted in 2018 found that 51% supported a change in the definition of a terminal illness for claiming benefits under special rules.

Only 12% oppose it. The polling also found that a third of GPs wrongly believe the SRTI process is for cancer patients only, excluding other patients from the SRTI process (Medeconnect polling for MND Association, October 2018). In light of these findings it is clear that the current definition is problematic for the health professionals trying to apply it.

4) <u>Health professionals have reported that assessors contact them to question submitted DS1500 forms</u>

Some doctors and other health professionals have told the MND Association that they have been contacted by disability assessors or the DWP querying the validity of a submitted DS1500 form. To inform the MND All-Party Parliamentary Group's 2017 report on PIP, the MND Association contacted clinicians and care coordinators at MND Care Centres to ask for their experiences of supporting SRTI claims. Out of 21 health professionals who responded, 13 said they had been contacted by assessors questioning prognosis for a PIP claim under SRTI.

One told us that "I frequently have calls from [assessment provider] after filling in the DS1500, asking if they have a terminal illness." Another stated that "we have tried to complete DS1500 forms for people with MND previously and it has been rejected, because the PIP assessors have decided they are expected to live longer than 6 months."

The Minister for Disabled People, Health and Work, Justin Tomlinson MP, recently confirmed in a response to a parliamentary question that "it is possible for a PIP claim made under special rules for terminal illness to be rejected as a special rules case by the Assessment Provider for not satisfying the terminally ill definition". (Response to PQ 245708, given April 30th 2019). This means that non-specialist assessment provider staff are overruling the decisions of clinicians who have direct knowledge of both the claimant and their condition. This demonstrates how the terminal illness criteria are used to exclude claimants from the process, even in cases where their application is supported by their clinician.

What should change?

In 2018, the Scottish Parliament passed the Social Security (Scotland) Act which changes the definition of terminal illness to one based on clinical judgement, thus removing the 6-month restriction. So, a claimant is determined as having a terminal illness if: “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”. We understand that guidance is now being developed to bring further clarity to how this change should be applied.

This will create a much fairer system in Scotland where people with a terminal illness with more than six months to live will qualify for SRTI. We would strongly support a similar legislative change to create a fairer system in all nations within the UK.

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. The MND Association is calling on all MPs to support the Bill.

Revisions to DS1500 guidance notes

In April 2019 the DWP announced revisions to the DS1500 guidance, aimed at softening the language around the six-month requirement. The revisions represent an improvement to the guidance and reflect the progress made through our campaign to draw attention to the flaws of the Special Rules process as it stands. However, the retention of the six-month rule in legislation limits the Department’s ability to improve the Special Rules system. The proposed new guidance will continue to make reference to the six-month criterion, limiting the impact of the revisions and allowing ongoing uncertainty around inherently unpredictable terminal conditions, such as MND. In addition, due to the legislative changes passed in Scotland in 2018, a two-tier system will develop unless the rest of the UK makes a similar change to the law. For these reasons, we continue to argue that a change to UK law is necessary to finally resolve this issue and ensure that all those who are terminally ill can access the benefits they need rapidly and sensitively.

About MND and the MND Association

1. Few conditions are as devastating as MND. It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.

2. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe. Speech is

usually affected, and many people will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia.

3. MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

4. A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult but is more common in older people. There are about 5,000 people living with MND in the UK.

5. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

10. MND Scotland

MND Scotland provides welfare rights advice to people affected by MND across Scotland. Feedback from this service tells us that people with MND are being failed by the Department for Work and Pensions (DWP) Special Rules system. In particular, the need to prove just 6 months life expectancy means that many of those with the illness are failing to be fast-tracked.

This is why MND Scotland successfully campaigned with Marie Curie to ensure that the Social Security (Scotland) Act 2018 had a definition of terminal illness based on clinical judgement rather than life expectancy.

APPG for Terminal Illness Inquiry

The APPG for Terminal Illness inquiry into the legal definition of terminal illness is most welcome and we are grateful for our invitation to respond.

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?

No – the current legal definition of being terminally ill as having six months left to live is definitely *not* fit for purpose. It unfairly excludes many people living with terminal conditions from accessing their benefits quickly, from the point of need.

There are many terminal conditions where it can be difficult, or near impossible, to predict when a person has entered the last six months of life. This includes Motor Neurone Disease (MND) but also heart failure, dementia, and chronic obstructive pulmonary disease (COPD).

Does the 6 month definition help or hinder people affected by terminal illness to receive the support that they need?

The 6 month definition *hinders* many people affected by terminal illness because it prevents them from accessing their benefits under the special rules system.

Special Rules

To access benefits under special rules, people with a terminal illness must submit a DWP DS1500 form, signed by their clinician, who must confirm that their death ‘can be reasonably expected’ within 6 months.

Accessing benefits under special rules means the terminally ill person will:

- have benefits fast-tracked, usually receiving their first payment currently within 4 weeks;
- receive their benefits at the highest rate;
- not have to undergo any further assessment;
- not be subjected to lengthy qualifying periods;
- be paid weekly in advance rather than monthly in arrears.

If a terminally ill person fails to secure a completed DS1500 form from their clinician, they will need to apply for their benefits under the standard route.

Standard route

If a person is not eligible for special rules, they must:
a. apply in the normal way with set qualifying periods and waits, currently, of up to 6 - 9 months for their benefits
b. face a much more intrusive face-to-face assessment based on their ability to perform 12 activities
c. receive their benefits monthly and in arrears.

Delays in accessing benefits like PIP *also* lead to delays in accessing Carers Allowance, Blue Badge, motability car scheme and increased premiums to means tested benefits such as Universal Credit, Housing Benefit, Council Tax reduction benefit, income related Employment Support Allowance, Income Support and tax credits.

MND and the '6 month definition'

MND is a rapidly progressing terminal illness, with just 20 months average life expectancy from diagnosis. Benefits for those affected are needed fast. However, many of those with the illness find themselves excluded from the fast-track special rules process. This is because 6 months life expectancy has no clinical manifestation in MND. Clinicians cannot confidently predict if someone with the illness has 6 months or less to live because there is no standard disease trajectory for MND. Understandably, many clinicians will not complete the DWP DS1500 form. Those who do often find their prognosis quizzed by the Independent Assessment Service (formerly ATOS), and sometimes rejected.

If a person with MND cannot obtain a DS1500 and access benefits under the DWP special rules, s/he will need to apply for benefits like Personal Independence Payment (PIP) under the standard route. This can mean a 9 month wait for benefits – almost half the average life expectancy, from diagnosis, of someone with MND – and a face-to-face interview with an assessor.

Carers Allowance is also delayed, as eligibility is dependent on benefits like PIP being in place. As a person with MND becomes rapidly more and more disabled, caring for someone with the illness quickly becomes a 24/7 role. Many carers will need to give up work to do so, creating an additional financial burden on families.

For someone with an illness like MND, whose condition will never improve, but only deteriorate until their death, the process is unfair and undignified.

Terminally ill people in Scotland

In Scotland, however, there is an additional concern. Whilst the Social Security (Scotland) Act 2018 secured a definition of terminal illness based on clinical judgement, this is only for benefits devolved to Scotland meaning terminally ill people and clinicians must deal with a two-tier system, with reserved benefits such as Universal Credit and Employment Support Allowance having to adhere to DWP rules.

About MND

Motor Neurone Disease (MND) is a rapidly progressing, muscle wasting, terminal illness. MND stops signals from the brain reaching the muscles. Muscles start to waste and weaken, and eventually stop working. This may cause someone to lose the ability to walk, talk, eat, drink or breathe unaided. Some people may also experience changes affecting their behaviour and ability to think and plan. Not everyone will develop all symptoms and how it affects individuals can vary significantly.

There is currently no cure or effective treatment for MND and the average life expectancy from diagnosis is just 20 months. On average almost 200 people are diagnosed each year in Scotland, 53% die within one year of diagnosis and 6.5% live for more than 5 years after diagnosis.* There are over 450 people in Scotland currently living with MND.

*data from the Scottish MND Register 2015 and 2016.

About MND Scotland

MND Scotland is the leading charity in Scotland providing care and support to people affected by Motor Neurone Disease (MND), as well as funding vital research into finding a cure. We campaign on behalf of people affected by MND, and raise awareness of the disease. People with MND are at the heart of everything we do, and we are committed to improving the lives of those affected now and determined to help find a cure for those affected in the future.

11. Scottish Partnership for Palliative Care

The Scottish Partnership for Palliative Care (SPPC) brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement. We also work to enable communities and individuals to support each other through the hard times which can come with death, dying and bereavement.

SPPC was founded 27 years ago and has grown to be a collaboration of over 100 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, all Integration Authorities, all the hospices, a range of professional associations, many national charities, local authorities, social care providers and universities.

Language and Terminology

Some standard definitions of palliative care and end of life care are shown in Appendix 1. The two WHO definitions describe what palliative care is but neither provides a very precise guide to who may have palliative care needs (either at individual or population level). Both state that palliative care is relevant or may start from the point of diagnosis – for some conditions this may be decades before the person dies. The GMC suggests that end of life care is relevant to people who are expected to die within 12 months. The difficulty with this approach is that it is often difficult to predict whether someone will die within the next year.

SPPC has suggested that one way of thinking about "palliative care" is to talk in terms of providing "good care" to people whose health is in irreversible decline or whose lives are coming to an inevitable close. Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making. However, palliative and end of life care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

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?

The current definition relies on a degree of prognostic certainty which is often difficult to attain.

Does the six month definition help or hinder people affected by terminal illness to receive the support that they need?

The six month definition appears to make it more difficult for people with conditions other than cancer to access benefits. These conditions often have a lower degree of prognostic certainty than cancer, and it is harder for clinicians to reach a judgement that the person has six months or less to live.

Other factors leading to differential access to benefits

In addition to the deficiencies in the current definition other factors are also at play in the differential access to benefits. The degrees of uncertainty involved in conditions such as heart failure, COPD, frailty often mean that people are not identified by professionals as approaching the end of life (with or without a timescale). There is also evidence that people themselves with these conditions are less likely to consider that they may be approaching the end of life compared to people with cancer and a comparable level of need. The result is that conversations between the pubic and professionals relating to end of life issues (including fast track access to benefits) are less likely to happen.

Different Approaches

Scottish Government is currently developing guidance to support implementation of a new definition of terminal illness for the purpose of determining edibility for benefits (fast track and higher rate).

“An individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if, having had regard to the (Chief Medical Officer’s (CMO) guidance), 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.”

The definition avoids any reference to timescales. The draft guidance adopts an approach which is based on a series of clinical indicators. The consultation on the draft guidance has just closed.

Appendix 1

World Health Organization Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

World Health Organization Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO’s definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

General Medical Council Definition of End of Life

“For the purposes of this guidance, patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

(a) advanced, progressive, incurable conditions

(b) general frailty and co-existing conditions that mean they are expected to die within 12 months

(c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition

(d) life-threatening acute conditions caused by sudden catastrophic events.”

12. Children’s Hospices Across Scotland (CHAS)

Children’s Hospices Across Scotland (CHAS) is the national provider of children’s hospice services. For over 25 years we’ve been offering a full family support service for babies, children and young people with life-shortening conditions across Scotland. This includes palliative and end of life care, family respite and support through our two hospices in Balloch and Kinross, our CHAS at Home services and hospitals.

Across Scotland, 15,949 babies, children and young people have life-shortening conditions. Of these, 5,671 had contact with a hospital team in the preceding year. Over 150 children and young people die each year in Scotland.1 Our ambition is to reach every family who needs us.

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?

CHAS believes that the current legal definition of being terminally ill in England and Wales (having six months left to live) as being unfit for purpose.

This definition is arbitrary and subjective and it is particularly problematic for people with certain conditions, such as MND, that do not follow a standard disease trajectory and the progression of the disease can vary significantly between individuals. The issues concerned with this definition and the impact and undignified process of individuals having to get the necessary support, often dying before they get it, is well documented.

On the 25 April 2018 the Scottish Government voted to change the definition of a terminal illness for the purpose of claiming benefits. The new system in Scotland will see someone defined as terminally ill if “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”.

CHAS is fully supportive of this new legal definition adopted in Scotland and urges the UK Government to make the same changes so that people across the UK who are terminally ill can get the support they need, when they need it.

Does the six month definition help or hinder people affected by terminal illness to receive the support that they need?

CHAS believes that the six months definition hinders people affected by terminal illness.

The six month definition is arbitrary and subjective which means that individuals who very much need the support often do not receive it until it is too late. In the UK Marie Currie estimate that 10 people die every day whilst waiting for the welfare benefits they need.

The new definition of terminal illness in Scotland is based on clinical judgement with no timescales... that means no six-month rule. This change means that many more terminally ill people in Scotland will start to access benefits quickly, without assessment and at the highest amount payable.

More worryingly the six month definition in England and Wales will cause a huge hindrance in the shape of a possible two tier system for claimants who are terminally ill in Scotland. Not all benefits are devolved to Scotland so for those benefits still reserved to Westminster, such as Universal Credit, Scottish people will still be subject to the six-month rule. This means that, depending on which social security benefits they are applying for, people in Scotland could face a two-tier system. This may be complex and confusing, with some people working with different requirements and definitions for different purposes.

CHAS believes that all regions of the UK should adopt the new legal definition of terminal illness as set out in the Social Security (Scotland) Act 2018 and scrap the six month rule. This will ensure that all individuals who are terminally ill can access the support that they need, when they need it.

13. Health and Social Care Alliance Scotland

The ALLIANCE welcomes activity that considers this important area and encourages the Committee to work closely with our member organisations Marie Curie Scotland, MND Scotland, the Scottish Partnership for Palliative Care and others to consider the UK Government's future approach.

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?

We believe that this definition is no longer fit for purpose and should be brought in line with the definition adopted in the Social Security (Scotland) Act 2018. This places a duty on Government to ensure that there will be no limit set on how long an individual has left to live before their condition is considered "terminal". The ALLIANCE supported this amendment to the draft legislation, originally proposed by Marie Curie Scotland and MND Scotland, which was subsequently adopted and amended in the name of the then Minister for Social Security, Jeane Freeman MSP.

As noted in Marie Curie and MND Scotland's Stage One briefing on the Social Security (Scotland) Bill , "6 months life expectancy has no clinical meaning in most terminal illnesses. The system only works for people with terminal cancer, because cancer has a clearly defined disease trajectory. As a result, many terminally ill people, including those with Motor Neurone Disease (MND), heart failure, dementia, and chronic obstructive pulmonary disease (COPD) fail to access the benefits under 'special rules', including the fast track system."

The change in policy ensures that the Scottish Government has a duty to recognise the inconsistent and changing nature of terminal illness as part of its consideration for eligibility for the three new elements of Disability Assistance (as proposed in its ongoing consultation on Disability Assistance).

We believe that by maintaining the six month time limit, that the UK Government is not appropriately recognising the reality of living with a terminal illness, as well as failing to recognise the inextricable link between the skills and expertise of health professionals in understanding and working with various terminal and long term conditions.

<u>Does the six month definition help or hinder people affected by terminal illness to receive the support that they need?</u>

Our members have told us that many of the people who live with terminal illness they work with have faced serious obstacles when trying to access social security entitlements. At present, the system of special rules is only working for people with a terminal cancer diagnosis. Statistics from the DWP show that that 95% of people accessing PIP via the special rules for the terminally ill have terminal cancer . This shows that there are flaws with the current system which should be changed.

For people living with conditions like MND, there is no standard disease trajectory. For those diagnosed with advanced forms of heart failure, nearly 90% die within one year. Average life expectancy from diagnosis, with MND, is 20 months. These terminally ill patients should not be expected to apply for benefits under the normal route. MND Scotland states that accessing PIP without a DS1500 can take up to 9 months.

The full impact of the change from six months to “no time limit” within the Scottish social security system is yet to be experienced by people living with terminal illness in Scotland. However, as the three elements of Disability Assistance are rolled out (with transition to the new system expected to continue until 2024), it is expected that the Scottish Government’s duty to ensure people living with terminal illness are entitled to access special rules will result in the fast tracking of their application and higher rates of assistance.

We also believe that this change better recognises the link between health, social care and social security. The Scottish legislation states that “a registered medical practitioner should assess whether the applicant has a progressive condition which can reasonably be expected to cause the person’s death, without stating a firm time-limit on the expected time of death.” We would like to see this further extended to other professionals working with the individual (including nursing staff) in future and would call on the Committee to consider if this could be achieved across the UK.

14. Maggie’s

I write on behalf of Maggie’s centre in Glasgow, where I am the full-time Benefits Advisor. Maggie’s provides a programme of evidence-based professional support–including benefits advice and representation–to anyone affected by cancer, whether they have cancer themselves, care for someone who does, or are bereaved.

Being sited next to the Beatson West of Scotland Cancer Centre, our centre serves the whole city of Glasgow and we also welcome centre-users from further afield: from south Ayrshire through to the Hebrides.

A substantial minority of our centre users have a life-limiting cancer diagnosis, or support someone who does: around 33% of the 18,000 visits we receive every year.

<u>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?</u>

In my professional view, the current legal definition is both poorly targeted and its ambiguity means it is misconstrued by the Department for Work & Pensions. It is not fit for purpose.

Today it is quite common for people with a progressive disease–whether cancer or any other condition–to be given no formal prognosis. I understand this is due to the difficulty for clinicians to predict in any scientific sense the outcomes of these types of conditions as well as treatment outcome probabilities.

Whereas it is normally possible for medical specialists to ascertain that a progressive condition will significantly shorten an individual’s life expectancy, there is an understandable reluctance to frame this within any type of time period.

More than this, it seems that especially with continuous welfare reform medical professionals often feel that they are expected to stay abreast of complicated social security issues rather than to more simply complete a medical report.

Many medical professionals are reluctant to suggest that life expectancy could fall as short as six months as this can be misinterpreted by patients and their families, even potentially jeopardising the possible benefits of ongoing interventions, and in some circumstances professionals are anxious about possible consequences against themselves as registered practitioners (even though these fears are broadly speaking unfounded).

As a representative of claimants with life-limiting diagnoses, it is noticeable that in communications from the DWP to medical professionals (whether public literature or in direct phone calls) the Department is keen to interpret the legal definition as “[having] less than six months to live” whereas a “reasonable expectation” (as the legislation says) that someone may pass away within that time period is clearly less restricted.

All of these issues combined routinely conspire against terminally ill claimants from accessing benefits as rapidly as possible, causing delays in application as well as anxiety surrounding ongoing claims.

When renewal of benefits (e.g. PIP) under the special rules is both legally and medically appropriate, I regularly see claimants being left with feelings of guilt about their own survivorship or anxiety that their ill health could be subject to challenge.

I would urge the APPG to consider recommending a new definition which is both less arbitrarily short and less ambiguously termed than the one in current use.

Does the six month definition help or hinder people affected by terminal illness to receive the support that they need?

The six month definition hinders the ability of many of those affected to receive the required support. I can think of no circumstances where the six month definition is more advantageous to a claimant than a less subjective definition would be.

Benefit claimants in some of the hardest circumstances imaginable face a potential labyrinth of complexity (as outlined above) often before even lodging a claim for their entitlements.

The arbitrary six-month definition in many instances inhibits claimants from managing their own benefit claims effectively. It wrongly deters some claimants from identifying themselves as terminally ill, and for others it can be so traumatic that it obstructs accessing legal entitlements altogether.

It appears this is becoming more pronounced in Universal Credit, where increased involvement is expected of terminally ill applicants unlike with the “legacy” benefits.

The six-month term of reference means that some claimants who have done better under treatment than expected go on to lose out on a benefit like Personal Independence Payment at renewal stage because doctors have been reluctant to re-issue a DS1500, despite it being arguably more pertinent now than before.

A significant part of my work as a Benefits Advisor in a healthcare setting is to coordinate with medical staff to progress claims, often in the absence of knowledge of the claimant themselves. This is very often medically appropriate, but for a large part produced by the language of terminal illness and specifically the “death sentence” that claimants report feeling the special rules’ six-month time-frame has given them.

From a Scottish perspective, I am concerned that this issue will become even more pronounced in coming years: with the Scottish Government (laudably, in my view) planning to revise its own legal definition of terminal illness, it is unclear how this will cohere with the main income-related or contribution-based ‘reserved’ benefits like Universal Credit and Employment & Support Allowance.

For example, it is conceivable that there will be many claimants who may satisfy the Scottish Government’s definition of terminal illness in order to claim its disability allowance, whereas they are unable to obtain the same recognition for the purpose of claiming DWP benefits.

15. Royal College of Nursing

The Royal College of Nursing (RCN) is the professional body and union for the Nursing Profession. Our members represent Nurses from across the workforce including those who work with people who have terminal and/or long term degenerating conditions and those requiring palliative care.

As an organisation, the RCN has been involved in a number of campaigns to review the current benefits system for people with who are dying and those with fluctuating, deteriorating and debilitating conditions such as Motor Neurone Disease and in particular those who are living with dementia. The RCN is a partner in the Continuing Care Coalition seeking reforms of the current Continuing Healthcare funding. In addition, the TUC and other trades unions including the RCN are campaigning for terminal conditions to be made a “protected characteristic”, meaning that employees facing the end of life should not be dismissed because of their condition which puts further stress and pressures on dying people and those that they love. https://www.dyingtowork.co.uk/

The TUC and other trades unions including the RCN are campaigning for terminal conditions to be made a “protected characteristic”, meaning that employees diagnosed with a terminal illness or condition should not be dismissed from their employment because of their condition https://www.dyingtowork.co.uk/

The RCN’s Membership Department supports nurses who are themselves ill and living with life limiting illnesses. We have included in our response on some of the information these members have provided us with which we hope will be of interest to the APPG in its inquiry.

Key Messages

The current definition of terminal illness being six-months is no longer fit for purpose particularly in the way that support, especially financial support, is offered to patients. As the APPG may know, many people wait inordinately long periods of time for benefits because they do not meet the current requirements leaving them living with significant hardship.

While the RCN accepts that the approach recently taken in Scotland is superior to that in England we would be concerned that a wholescale adoption of the Scottish approach would

I. effectively remove the current fast-track process and

II. place responsibility on the medical profession to provide the DWP with very detailed reports on care and mobility needs of the individual.

The RCN position is that future systems/processes refer to life limiting illnesses and/or debilitative illness rather than terminal illness. Additionally the RCN would assert that access to financial support is not restricted to those with a judged 6-month life span but rather is extended to those people able to live with their illness while continuing to receive treatment but are clearly suffering financially because of their increasing debilitation.

The RCN would also caution that care is taken to consider any unintended consequences likely to emanate from a change in legal definition including potential implications for insurance policies, employment law, mortgages etc.

Background information

Quantifying life expectancy in terminally ill patients is fraught with difficulties and if pushed to quantify clinicians are often 'proven wrong'. Many clinicians feel that a discussion with patients about their prognosis at an early stage including the issue of likely time to death with an associated parallel plan is more helpful. This should also include discussions about financial support, which can be a primary concern for people especially if they and/or their carers are having to give up work.

The current legal definition of terminal illness and the acceptance of the six month life expectancy was accepted as being fit for purpose at a time when it was commonplace for this to refer to people who in the main were dying from cancer. At that time there was not an appreciation of the other complex long-term degenerative conditions, which would also have rendered people terminally ill with less than six months to live. Additionally since the adoption of the current definition diagnostic and treatment advances have led to better and earlier diagnosis, treatment and prognosis resulting in many people living for longer periods of time with diagnosed debilitative disease.

This in itself has imposed severe financial difficulties for those people for longer periods of time.

The system in England at present is reliant on a clinician determining whether a person is likely to die in the next six months and completing the necessary forms to progress fast track access to benefits to support the individual financially in the last months of their life. Once benefits have been awarded, they remain in place until the person dies even if this exceeds six months. However, where a clinician judges that someone may live beyond the current 6-month rule, that individual, despite suffering severe hardship resulting from their illness does not have access to financial support.

For those with a life limiting illness, who have a clear six months prognosis, the current rules work well. However, where there is not a clear indication from the clinician as to how long someone might normally be expected to live, individuals have to resubmit an application without medical assessment or return to their consultant/doctor to request a clearer timeline. Both add more time to an individual experiencing financial hardship and adding more stress to an already stressful situation.

Some further points the RCN would add are:

1.The six months definition creates an inequality of access for people dying from non-malignant diseases where prognosis of likely time to death can be exceptionally difficult such as dementia and a range of neurological diseases.

2.The six months definition is helpful to some people with cancer but detrimental to others. Health and care professionals do tend to identify some diseases as having a short prognosis whilst forgetting to look at the "whole picture" for people with co-morbidity.

3.The Care Quality Commission and the General Medical Council define End of Life Care as anyone with a probable prognosis of one year or less. The RCN believes that the twelve month timescale will still be problematic but recognises that regulators and professional bodies have a place to play in influencing the definitions.

Conclusion

In conclusion the RCN believes that the term terminal is neither appropriate nor helpful when talking about life limiting illnesses or impending death. The RCN would suggest that ‘in the last years of life’ would be a more appropriate terminology. There are a number of illnesses, which will result in death but over a longer trajectory and those people and their families should have access to benefits in a timely way and not be subjected to additional burdensome assessment. The RCN welcomes the review and believes that the legislation should be updated to reflect the changes and advances that have occurred in diagnosis, prognosis and treatment since the legislation was put in place. This, however, should not be to the detriment of people who are facing an uncertain future nor be a covert way of reducing the demand on the benefits system.

16. Royal College of Physicians

The RCP appreciates the opportunity to contribute to this inquiry. We collected feedback from the Joint specialist committee for palliative medicine and the RCP/British Geriatrics Society committee.

The legal definition of terminally ill is not in keeping with the definition of ‘end of life’. In healthcare, people are considered to be approaching the ‘end of life’ when they are likely to die within the next twelve months. The General Medical Council states:

Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes those patients whose death is expected within hours or days; those who have advanced, progressive incurable conditions; those with general frailty and co-existing conditions that mean they are expected to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening acute conditions caused by sudden catastrophic events. The term ‘approaching the end of life’ can also apply to extremely premature neonates whose prospects for survival are known to be very poor, and patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment and care may lead to their death

The RCP believes access to support would ideally be based on need, not prognosis. Need can vary from person to person, and over time for the same person. Variation may be due to a new drug or treatment becoming available, or the psychological impact of diagnosis or prognosis. And prognosis can be difficult, particularly in the case of older people living with frailty and multiple long term conditions.

About the RCP

The RCP plays a leading role in the delivery of high-quality patient care by setting standards of medical practice and promoting clinical excellence. We provide physicians in the UK and overseas with education, training and support throughout their careers. As an independent body representing over 36,000 fellows and members worldwide, we advise and work with government, the public, patients and other professions to improve health and healthcare. Our primary interest is in building a health system that delivers high-quality care for patients.

17. Royal College of GPs

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?

84% No

8% Yes

8% Unsure

Yes – 2. It is very difficult to predict actually when a terminally ill patient will die. Some patients with multiple metastases may still be alive beyond six months with the advancements on the treatment options. For the purpose of fast-tracking still six months is fit for purpose as up to 80 to 90% will follow this tread.

No – 21. No. As described, changes in treatment require this to be updated.

No. For exactly the reasons you have outlined. A lot of terminally ill people are living longer than my younger self would have predicted 10-15 years ago.

No, this is such an arbitrary measure and very subjective. Clinical judgement as to who would benefit from being fast-tracker due to a life-limiting illness seems far more appropriate.

No, because the 6-month cut off is entirely artificial. Patients with metastatic cancer have a terminal diagnosis yet some of whom can live in excess of 6 months, by one day or a few months. Prognostication is known to be inaccurate just as predicting the future, so how can a strict cut-off date be dependent on an educated surmise?

No. I am finding that increasing number of patients have had a DS1500 and are still alive after 18 months or more and then we are asked if a DS1500 is appropriate-As these patients are more likely to die in the next 6 months than they were 18 months ago, I always say they should continue to receive the benefits

No. The changing picture of death and dying with frailty and dementia and organ failure causes predominating means prognostication is much harder yet function disability and the need for care for longer is far greater for these people

No. It is extremely difficult to judge this even with SPICT/ prognostic indicators.

No. With the rise in co-morbidity it is becoming more and more difficult to predict when a person is in their final six months of life.

No. In the adult world the system is flawed for both oncology and non-oncology patients. Currently it is very difficult to be accurate with prognosis from most cancers bar brain tumours. Current treatments mean that life expectancy is often much longer than we predict. As a result will often issue DS 1500 forms only to find the patient is still alive nine or 12 months later. With non-oncology patients, particularly heart failure and neuro degenerative patients, have a high degree of need for support which the emergency attendance allowance allows some to access but where the prognosis may run into a year or more.

In terms of children the issues even more complex. Children with cancers are often life threatened during treatment and as a result parents will stop working to be with the children. This leads to major financial distress for the families. Because these events can occur so quickly it can take a long time for benefits to come through. Children with neurodegenerative conditions show a decline over many years with episodes of severe illness which are life-threatening.

No. Comments: Agree with the comments made that this definition now does not reflect advances in medical care and that a number of patients live with terminal illness for significant periods of time. In addition non cancer diagnoses are much more difficult to predict/define a prognosis

No. as we can never be certain of timescale and it takes a long time to process benefit applications. Often patients have passed away by the time the benefits are granted. Terminally ill patients are those for whom we have no curative or life prolonging treatment to offer.

No. Patients can be terminally ill for much longer than 6 months, and some illnesses have very unpredictable prognoses.

Unsure -2. My understanding is that the six months is not about the definition of terminal illness but the prognosis that is required in order to be eligible for benefits (i.e. that is the amount of money that the DHSS can afford to fund)

Terminally ill is a good term to indicate a person is going to die of a disorder as it is not curable but is not a good term to determine who should be eligible for benefits as above describes, as it does not indicate a timed prognosis.

Does the six month definition help or hinder people affected by terminal illness to receive the support that they need?

68% Hinders

16% Helps

16% Unsure

Helps – 4. Comments: it makes it easier to access those benefits, less stressful for the family and provide and framework for health professionals.

Helps in most cases at the present time but is becoming much more difficult to assess in some cases especially with the improved mortality of certain disorders and will become more so. I can think of at least 3 patients of mine I would have been content to sign a ds1500 on, but are still here 2-3 years later due to a good response to treatment. (which is good news but makes the issue of benefits more complicated)

Hinders - 17. Comments: Particularly with increasing cancer survival and non-cancer diagnoses

Hinders. I tend to ignore the 6 month rule and if someone has a terminal diagnosis, their life is shortened by the diagnosis and currently not functioning, not going to improve, I pragmatically fill in the form.

Hinders, does not allow common sense to be applied to individual situations.

It in fact upsets a lot of patients and carers to read about the 6 month life expectancy. If the 6 month cut off is not really a valid definition of a terminal illness, then by definition it does not help some people to receive the support they need.

Hinders for the same reasons as above plus timescales like this generally are not good practice and don’t help in fostering trust and hope

As above - many people live with their terminal illness for some years but progressing to further advancing disease and the consequences of their illness and treatment

It hinders people, as it is often too late in their disease trajectory for any additional funds to have a meaningful impact on their quality of life

A six months definition has a detrimental effect on many patients. It may take away hope for some regarding their prognosis and I have known patient who worry that if they live for more than six months that they will have to pay back any benefits they have received.

Hinders. Locally if patients are identified as having less than 3 months to live they can access fast track funding. If not – it can take months despite being very ill.

Hinders. It is very hard to know when the 6 month "stage" begins. Some people may worry they are doing wrong by filling out DS1500 too soon so it then may not be done in time.

Unsure – 4. I am not sure if the definition does help/hinder patients. If I am asked to do a DS1500 and there is a fair probability of death within 6 months I will always sign the DS1500 form

I suspect many people don't get the benefits they are entitled to towards the end of life because the life-limiting nature of their condition / possibility of dying is not discussed. I'm not sure it's the definition of terminal illness that's the problem, it could be more to do with lack of time for conversations and awareness of the benefits that people could be accessing in primary care.

Helps some hinders others. We have all also had patients that outlive the 6 months but are still terminal.

It obviously helps some, where diagnosis and EoL follow closely but not others and is therefore inequitable, particularly cancer v non-cancer diagnoses for the reasons stated. The process itself works well as far as I am aware.

It would also be helpful to understand as a GP if you are supportive of a move to GPs using our ‘clinical judgement’ (with the aid of supportive indicators/tools) to support referral to ‘fast-track’ benefits? Yes/ No (delete as appropriate)

84% Yes

8% No

8% Unsure

No – 2.No. I do not want to be held accountable for making these decisions

No. I do not think GPs should be responsible for judging who is and is not eligible for benefits on the wider scale as it interferes with the Doctor / Patient relationship and is not the role we should have. More work should be done by the Government agencies to assess patients with the help from GPs and specialists giving clinical details as requested.

Yes – 20. Yes. Definitely. Allowing GPs to use their knowledge of the patient and their experience to judge each individual situation is a much more appropriate way to ensure patients get the timely support they need.

Yes. I am supportive of the move to the decision based on clinical judgement.

Yes. this would be a much better system but need massive workforce education and training for consistent practice

Yes. I think this could be very helpful for patients and their families, and GPs

Yes. There are many terminal diagnoses but the patient may not be in the terminal phase of the disease process. There should be a process where certain diseases are accepted as terminal, and therefore a fast track referral is acceptable. A patient may have a diagnosis but is still able to work and live normally therefore a GP would decide a fast track is not needed.

Yes. Living with a label of terminal is hard enough and, in my opinion, the GP should know the patient well and be supporting them through their illness, treatment and difficulties so best placed to refer for fast track benefits

Yes. I prefer this approach so we can have person centred care. One possible down side is possible pressure to fill in form inappropriately.

Yes. I would be supportive of the idea of using the concept of clinical judgement. I would caution you around the use of aids for supportive indicators and tools particularly in children because of their poor reliability in terms of prognosis.

Yes. Note that it is not only GPs, but also community nursing staff or hospice staff are the people currently completing the DS1500. They are all in a position to use their clinical judgement in these situations. There are limitations on who is eligible to apply for DS1500, perhaps that could also be reviewed.

Yes. I think this would be a great idea, in our area the community Macmillan nurse are also heavily involved with prompting us to fill out forms and I think they and the CNS nurses in hospital should be involved. The new electronic version of the DS1500 that we can do in primary care is a great step forward and I would like to see any new system use this system again.

Yes. However, the process needs to be quick and easy for GPs to complete to ensure patients benefit

Yes as we are best placed to know our patients and their needs. A fast-track system would be welcomed by healthcare professionals and patients and their loved ones.

Yes. But I would not want to be the only member of the team able to make that decision. I see the GP as very much part of a multi-disciplinary community team.

Yes. We often do assess patients and request for fast track.

Yes. As GPs we are very used to using clinical judgement for these sort of decisions - also as we often know patients well over many years it is easier for us to see the pace of change/ deterioration that is happening.

Unsure Or Yes/No not specifically answered – 2. I think this would be very likely to be abused and clinical judgement of what exactly? Currently if someone ‘could’ die within six months then they are eligible, it is not compulsory that they do die in six months! The variability of decision making and expertise may make this inequitable.

18. Association of Palliative Care Social Workers

The Association of Palliative Care Social Workers believes that the current definition is not fit for purpose. We are concerned that without the proposed amendment, to lift the time restriction of six months, the current legal definition of terminal illness will remain in place. Since this definition of terminal illness was introduced, improvements in treatment means that people are living longer with terminal illnesses. Unfortunately, this also means that in many cases they are suffering from severe symptoms and disabilities for longer. People living with terminal illnesses and their families often encounter financial hardship for far longer than 6 months prior to death; for example, their illness may mean that they and/or their carers are forced to reduce or stop working, and there are often significant expenses involved in managing a serious illness. The stress and anxiety caused by this financial burden presents huge challenges to people at a time in their lives which is already inherently distressing and traumatic. This means that they and their families are faced with much lower incomes but also with higher expenses for much longer than six months and at a time in their lives which is inherently distressing and traumatic.

Does the six months definition help or hinder people affected by terminal illness to receive the support that they need?

The six months definition requires people to prove that they have six months or less to live to receive benefits under the ‘special rules’ for terminal illness. This limits the number of terminally ill people in the UK able to access social security quickly and easily.

The current system mainly works for people with some terminal cancers. Cancer has a clearly defined disease trajectory and it is easier to predict when someone is in the last six months of life, giving clinicians confidence to sign off the DS1500. However, six months has no clinical meaning in most terminal illnesses, because there is no clearly defined disease trajectory. As a result, many terminally ill people, including those with Motor Neuron Disease, heart failure and Chronic Obstructive Pulmonary Disease fail to access benefits under special rules, meaning they must wait much longer for their benefits and have to travel to go through face to face assessments. This position is discriminatory and, in our view, lacks humanity.

If the proposed amendment is agreed, this will allow more terminally ill people to receive benefits quickly, fairly and in a more sensitive way. It will also assist clinicians to begin conversations about death and dying and bereavement earlier with their patient and the patient’s families, helping to support better care with greater planning. It will more closely align with government strategy such as the “Independent Review of Choice in End of Life Care”.

The Association of Palliative Care Social Workers believes that a terminal illness definition based on clinical judgement and the need of the patient would be ideal to support the administration of social security benefits in the UK. If, however, terminal illness must be defined in terms of life expectancy then two years would be a fairer time-scale, covering more terminally ill people than the current system.

19. Hospice UK

Hospice UK is the national charity for hospice care. We champion and support the work of more than 200 member organisations, which provide hospice care across the UK, so that they can deliver the highest quality of care to people with terminal or life limiting conditions, and support their families.

Hospice care includes inpatient services, day services, hospice at home, community nursing and more. We estimate that across the UK, 200,000 people use hospice services every year, and many more families and carers are supported by hospice care.

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?

Under the current system, people who are diagnosed as having six months to live are able to access welfare benefits via a fast track system. This fast track system is welcome and an important part of the support people need during a terminal illness.

However, the current legal definition of terminal illness, which requires that the individual “can reasonably be expected [to die] within 6 months”, is arbitrary and lacks clinical relevance. A person may be in need of support as a result of a condition or disease, which is terminal, for a period longer than six months. Individuals with diseases or conditions which do not follow a predictable linear trajectory, and where the expression of the disease or condition can vary significantly between individuals, can fall outside of the limited scope of a six-month legalistic definition and miss out on the benefits intended to assist them. The definition thus excludes people whose disease or condition progresses differently.

Individuals with terminal illnesses other than cancer or conditions where progression is harder to predict, such as individuals with neurological conditions or organ failure, are particularly likely to be overlooked by the six-month definition.

For these reasons, the current legal definition of terminal illness does not meet its intended purpose as many legitimate claimants with terminal conditions are not having their needs met as a result of the current definition.

Does the six month definition help or hinder people affected by terminal illness to receive the support that they need?

The six-month definition excludes individuals affected by terminal illness who do not fit the narrow six-month criteria, preventing them from benefiting from fast-tracked access to welfare benefits.

Scottish policy makers have already noted and addressed the inequalities inherent within the six-month definition, adopting a new definition in April 2018. The new system defines terminal illness as when “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.” The removal of any reference to a time-restriction ensures that no individuals will be failed or refused the assistance they need at their most vulnerable.

Since the new definition has been introduced there has been a positive response from all key stakeholders to the new terminal illness provision. (https://www.gov.scot/policies/social-security/terminal-illness/)

It is Hospice UK’s opinion that a similar definition should be introduced to the rest of the UK to ensure all those affected by terminal illness can access the support that they need.

Summary

The current definition of terminal illness for accessing fast-track personal independence payments does not deliver the ambition to ensure people with terminal illnesses are able to access support in a timely and simple way and must be updated. The six-month definition means that vulnerable individuals are not receiving the support they need. A definition of terminal illness based on the clinical judgement of a registered medical professional rather than on an arbitrary time-restriction will ensure all those with terminal conditions receive the support they need.

20. Marie Curie

Marie Curie is a leader in the provision of care and support to people affected by terminal illnesses in the U.K. We provide a range of services including nine Marie Curie hospices across the U.K., Nursing Services and Helper Services. Each year we provide care and support to more than 40,000 people living with a terminal illness, their carers and loved ones.

Executive Summary

People living with terminal illnesses can apply for social security payments under the Special Rules for Terminal Illness, but current social security law defines someone as terminally ill only if they have six months or less to live.

Those terminally ill people who apply for benefits under the Special Rules are likely to have a significantly different experience than those who claim through the standard route. Their claim will be processed much quicker and they will not have to go through face-to-face assessments, Work Capability Assessments or sessions with job coaches to receive their benefits. Depending on the benefit, they also will not be subjected to the normal qualifying periods, and they will receive an enhanced or higher award in their payments.

The Special Rules allow terminally ill claimants to access the support they need quickly, with as little bureaucratic interference as possible – supporting them to enjoy a better quality of life during the time they have left. However, there is a wealth of evidence showing that the six month life expectancy criterion is excluding many terminally ill people with unpredictable conditions from applying for benefits under the Special Rules.

For many terminal illnesses, particularly non-cancer conditions like motor neurone disease (MND), chronic heart failure or chronic obstructive pulmonary disease (COPD), accurate prognosis can be difficult because of the unpredictable trajectories of these conditions. The rate of progression can vary, and patients may be expected to live for a longer period but die within six months due to a sudden decline in their condition. Many of these people are therefore prevented from applying for benefits under the Special Rules because it is simply too difficult for their doctor to predict whether or not they are in the last six months of life.

Those terminally ill claimants who are forced to apply under the normal rules are being put through intrusive benefit assessments and sessions with job coaches – with some even being passed as fit for work. The delays associated with standard applications also means that some terminally ill claimants are not receiving their benefits until the advanced or end of life stages of their condition, or, in the worse cases, until after they have died.

Marie Curie believes the legal definition of terminal illness needs to be reformed. We are calling for the six month rule to be scrapped, and replaced with a new definition that is based on clinical judgement. This would follow the new definition of terminal illness set out in the Social Security (Scotland) Act 2018 – creating a much more compassionate system which would allow many more terminally ill people to get quick and straightforward access to the welfare support they need, when they need it.

The pages that follow include real-life accounts of terminally ill people's experiences of the benefits system. They have been shared with Marie Curie over the last several months, and demonstrate the impact that the six month rule is having on terminally ill people and their loved ones throughout the U.K.

Applying for social security with a terminal illness

People living with terminal illnesses can apply for social security payments like Personal Independence Payments (PIP), Universal Credit, Employment and Support Allowance (ESA) and Attendance Allowance under the Special Rules for Terminal Illness (SRTI).

The definition of terminal illness used to determine eligibility for a Special Rules claim is: "a progressive disease and death in consequence of that disease can reasonably be expected within six months." In other words, only those with an estimated life expectancy of six months or less are eligible to make a claim for social security benefits under the Special Rules.

People claiming under SRTI are encouraged to get a DS1500 medical report from their GP, consultant or specialist nurse to support their claim. DS1500s provide information about the person's condition and current/future treatment. If a DS1500 report is not provided, additional medical evidence may be required.

Terminally ill people who are eligible for social security payments under the Special Rules are likely to have a significantly different experience than those who aren't, e.g.:

Personal Independence Payments

SRTI claimants:

o will not have to complete the 'How your disability affects you' form;

o will not need to attend a face-to-face assessment;

o will be entitled to the enhanced rate of the Daily Living component of PIP without having to satisfy the normal three month qualifying period;

o will have their claim processed much quicker than normal claims; in Great Britain, average clearance times for new claims are 10 weeks under the normal rules and 5 working days under SRTI. [1] In Northern Ireland, the average clearance period is 13 weeks for normal claims and 2 weeks for SRTI claims. [2]

Universal Credit

SRTI claimants:

o will not have to take part in a Work Capability Assessment;

o will automatically be treated as having Limited Capability for Work-Related Activity – meaning they will receive a work capability amount (over £300 per month) in their UC award, and will not have to attend sessions with job coaches or fulfil work requirements to continue receiving their payments.

Employment and Support Allowance

SRTI claimants:

o will not have to take part in a Work Capability Assessment;

o will automatically be put in the Support Group without serving the usual 13-week assessment phase. As a result of being in the support group, any award of contributory ESA will also not be subject to the usual 12-month time limit.

For those who are eligible, the Special Rules for Terminal Illness allow claimants to access the support they need quickly, with as little bureaucratic interference as possible – supporting them to enjoy a better quality of life during the time they have left.

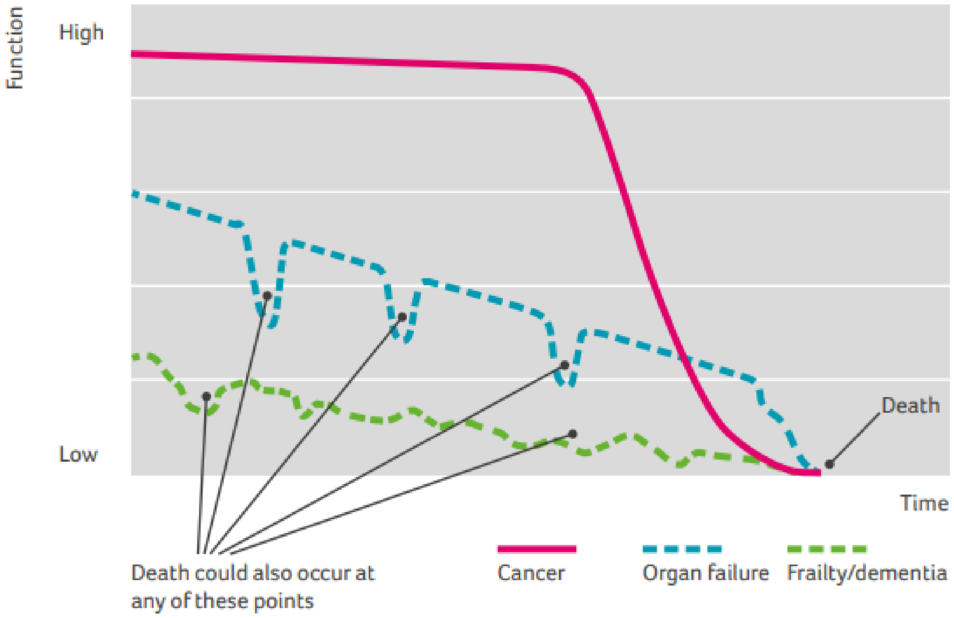
A terminal illness diagnosis has an enormous, life-changing impact on patients and their loved ones; quick and easy access to financial support can provide important peace of mind during an otherwise uncertain and traumatic time.

Who is being excluded?

We believe that, by using a definition of terminal illness that is tied to a life expectancy of six months or less, many legitimate claimants are excluded from applying for welfare support under the Special Rules for Terminal Illness.

For many terminal illnesses, particularly non-cancer conditions like motor neurone disease (MND), chronic heart failure, chronic obstructive pulmonary disease (COPD) and dementia, accurate prognosis can be difficult because of the unpredictable trajectories of these conditions. The rate of progression can vary, and patients may be expected to live for a longer period but die within six months due to a sudden decline in their condition (Chart 1).

Quantitative evidence reinforces how difficult it is for medical professionals to provide accurate predictions of life expectancy for people with terminal illnesses. For example, research into prognostic estimates of life expectancy for over 8,000 palliative patients found that accuracy varied from 23% to 78%. [3]



“My family survived with benefits during my husband’s last months. His anxiety about finances was huge for the children… but the benefits eased this somewhat.”

“My mum died with terminal cancer… [She] was lucky enough to be assessed and awarded but I couldn’t imagine how she would’ve coped if she didn’t.”

Example: Motor Neurone Disease

MND affects up to 5,000 adults in the U.K. at any one time, with just under 2,200 people dying from the disease every year. MND is a fatal, rapidly progressing disease of the brain and central nervous system. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. [4]

MND kills a third of people within a year and more than half within two years of diagnosis, but it is a highly unpredictable condition and it is extremely difficult for clinicians to give an accurate estimate of life expectancy for individual cases.

Example: Chronic heart failure

Between 30-40% of people with advanced heart failure will die within a year, [5] and the disease trajectory is characterised by sudden dips in functioning from which the patient could die or recover. This makes prognosis difficult, and widely used tools have been shown to be inaccurate at predicting survival in periods of less than 12 months. [6]

The existing definition of terminal illness was introduced by the U.K. Parliament in 1990 with limited clinical input. Our understanding of terminal illness has improved in the nearly 30 years since the introduction of the definition. The way people die has changed as well – people are much more likely to live longer with multiple conditions, making prognostication even more challenging.

There is significant evidence that the current definition is only really working for patients with a more predictable disease trajectory, such as some of the more common types of cancer:

o Latest available statistics show that, in Great Britain, 90% of the PIP claims awarded under SRTI are for people with cancer. [7] In Northern Ireland, the proportion is 85%. [8] This is despite cancer accounting for less than one third of all deaths across the U.K.

o In GB, only 45% of PIP awards for people with MND were claimed under the Special Rules, despite MND being terminal in all cases. [7]

o Between 2013 and 2018 in England, Wales and Scotland, DWP refused PIP claims from 8,010 people who went on to die within six months. [9] During the same period, over 17,000 people died waiting for their PIP claim to be determined. [10]

Those terminally ill people who are being excluded from applying for benefits under the Special Rules are having to claim through the standard process. They may have to endure intrusive face-to-face assessments and Work Capability Assessments to access the benefits they are entitled to, with some even been passed as fit for work. This is unfair, cruel and inhumane – causing significant distress and frustration for people and their loved ones and, in some cases, contributing to a worsening of the person's health.

The long wait for payments associated with normal rules applications also has a unique impact on terminally ill people. Time is a luxury they usually don't have, and delays are meaning that some terminally ill claimants are not receiving their benefits until the advanced or end of life stages of their condition. They may spend their final weeks and months fighting against the bureaucracy of the social security system. In some cases, they may even end up dying before they receive their first payment.

It is important to remember that the vast majority of the people we are referring to will be eligible to receive social security payments anyway. The problem is that, because of the arbitrary and unfair six month rule, they are being made to wait longer and put through stressful assessments in order to receive their payments.

"My son died with a brain tumour at the age of 37. He was permanently worried about benefits and all the threats to assess him for work… Luckily he had us to fight his corner, many people have no one."

"My mum recently passed away after battling MND… Only a few weeks before Christmas the assessors came round with a ridiculous 50-page document and spent 3 hours going through it. Afterwards my mum was left physically and mentally exhausted. It is not acceptable."

"When my mum was dying of stage 4 stomach cancer she didn't receive her first payment until after she had passed away."

"My partner lost his battle with MND three and a half years ago. We had to wait 8 months for any financial support. I cannot begin to describe how stressful it all was."

"We are waiting for a PIP assessment for my husband who has stage 4 brain cancer. The worry about this assessment has been going on now for about a year and has caused major anxiety… he should not be put through this stress. We already have more than enough to cope with."

Lorraine's story

Lorraine Cox, 39, from Enniskillen, Northern Ireland, was diagnosed with motor neurone disease in summer 2018. 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, but 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 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.

“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.

“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.”

A fairer definition of terminal illness: the Scottish approach

Marie Curie is calling for a new definition of terminal illness that is based on the judgement of medical professionals, not a narrow estimation of life expectancy. We want to see the six month life expectancy criterion removed entirely.

This model would follow the approach taken in the Social Security (Scotland) Act 2018. Under the Act, there is no limit set on how long a person with a terminal illness is expected to live before they can apply for PIP and Attendance Allowance under SRTI (Universal Credit and ESA remain reserved to Westminster). Instead, medical professionals will be able to use their clinical judgement to determine when someone is terminally ill for the purpose of applying for benefits.

Under the definition in the Social Security (Scotland) Act 2018:

“an individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if… 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.” [11]

Last year the Chief Medical Officer in Scotland established a working group of health and social care professionals, academics and other stakeholders. The group has been developing guidance to help health professionals make clinical judgements about terminal illness for the purpose of determining eligibility for benefits under the Special Rules. A public consultation on the guidance closed on 19 April 2019.

The final guidance is expected to be published in summer 2019, with the new definition of terminal illness coming into effect with the introduction of Disability Assistance for Older People (replacing Attendance Allowance) by the end of 2020.

It is critical that this same approach is adopted across the rest of the U.K. This is a much fairer, more compassionate definition of terminal illness which will allow many more terminally ill people to quickly access the social security support they need, when they need it – without having to endure intrusive assessments and fill in complicated forms.

This would also have important implications for Scotland, as terminally ill people in Scotland who are applying for Universal Credit and ESA currently still have to meet the six month life expectancy criterion to qualify under the Special Rules. This means that some terminally ill people in Scotland will face a two-tier social security system – causing significant confusion and adding even more stress to the application process.

Support for change

There is strong support among health and social care professionals and other experts across the U.K. for a new definition of terminal illness based on clinical judgement:

o A U.K.-wide poll in November 2018 showed that seven in 10 neurologists (73%) and more than half of GPs (51%) support the reform of the Special Rules criteria to remove the six month life expectancy criterion. [12]

o In Scotland, more than 50 clinicians signed an open letter in the Times Scotland in April 2018 calling for a new definition of terminal illness based on clinical judgement. [13]

o In Northern Ireland, 60 health and social care professionals signed an open letter in the Belfast Telegraph in June 2018, arguing that people with conditions like motor neurone disease and chronic heart failure are missing out on accessing PIP via the Special Rules because of the unpredictable nature of their conditions. The letter called for the rules to be reformed in Northern Ireland in line with the clinical judgement model in Scotland. [14]

o An independent review of the PIP assessment process in Northern Ireland in 2018 recommended that the six month rule be replaced with a system based on the judgement of clinicians. [15]

Context in England and Wales, Northern Ireland

England and Wales

In Westminster, Madeleine Moon MP introduced the Access to Welfare (Terminal Illness Definition) Bill in July 2018. The bill seeks to change the definition of terminal illness used in social security law – replacing the six month life expectancy criterion with a system based on clinical judgement, like in Scotland. The bill has received support from over 150 MPs representing every party in the House of Commons.

To date, the Government has not supported the bill or introduced any of its own legislation to change the definition of terminal illness. Efforts have been made instead to change the DS1500 form, to make the language around how and when clinicians can use the form more flexible. [16] Marie Curie contributed to and welcomes these efforts, but we are clear that any changes to the DS1500 form do not alter the existing legal definition of terminal illness. As long as this definition remains enshrined in law, health and social care professionals will stick to it, and many terminally ill people will continue to miss out on speedy, straightforward access to welfare support.

The Government has also discussed finding a solution to the issue within the existing legislative framework, including through the Severe Conditions Criteria under Universal Credit and ESA. [17] Marie Curie does not believe this is an acceptable solution, because many terminally ill claimants will still have to go through a Work Capability Assessment before they can qualify under the Severe Conditions Criteria.

Northern Ireland

Marie Curie's campaign for a new definition of terminal illness based on clinical judgement has received strong cross-party support in Northern Ireland. Last year, representatives of the largest parties in Northern Ireland wrote to the Permanent Secretary of the Department for Communities, which is responsible for welfare policy, calling for a working group to be established to review the definition of terminal illness and begin preparatory work for the introduction of a new system similar to Scotland's. [18]

Despite this support, change has not been possible due to the lack of a sitting Assembly and Executive. Social security law in Northern Ireland is maintained in parity with provision brought forward by the Department for Work and Pensions – unless the Executive and Assembly determine otherwise. The Department for Communities has stated that any change or review of the definition of terminal illness would need to be approved by an Executive Minister. Terminally ill people in Northern Ireland are therefore relying on legislators in Westminster to deliver change.

Conclusion

The existing legal definition of terminal illness is outdated, arbitrary and unfair. It is causing many terminally ill people to miss out on fast and straightforward access to welfare support – forcing them to endure intrusive assessments and long delays to access their payments.

Terminally ill people should not have to spend the limited time they have left fighting against the bureaucracy of the social security system. Marie Curie is calling for the six month rule to be scrapped, and replaced with a new definition of terminal illness that is based on clinical judgement. This is a much more compassionate model which would allow many more terminally ill people to get quick and straightforward access to the welfare support they need, when they need it.

21. Brain Tumour Research

Brain Tumour Research is grateful to the All-Party Parliamentary Group for Terminal Illness (APPGTI) for the chance to make a submission to this Inquiry. Parts of our response are based on our work with the brain tumour community, in support of an Inquiry undertaken by the All-Party Parliamentary Group on Brain Tumours, which examined the financial costs of brain tumours;

For the purpose of gaining fast-access to benefits, the current legal definition of terminal illness is not fit for purpose. It is too arbitrary to be applicable to those suffering from an extremely complex, unpredictable and degenerative condition such as brain tumours for which few effective treatments are available to mitigate the progression of the disease;

The six-month timeframe imposed by the current legal definition should instead be replaced by the prognosis of a clinician, as has been legislated for in Scotland. Expert medical opinions as to whether a diagnosis should be considered terminal will always be more relevant to brain tumour patients than any timeframe imposed by legislation;

The six-month definition is a great hindrance to terminal brain tumour patients when attempting to access the support they need. Although their condition is often terminal, they may survive (having to cope with the revocation of their driving licence), often in a state of serious illness, beyond six months. For those patients diagnosed with a glioblastoma, an aggressive form of brain tumour, there is an average life expectancy of 12 - 18 months;

This means that at the point they begin to need financial support, brain tumour patients rarely fulfil the six-month life expectancy criteria;

These terminal brain tumour patients are then required to apply for benefits via the normal route, which leads to a long-wait (all whilst their life expectancy diminishes) and the requirement to undergo onerous application procedures. With little to no prospect of recovery, which could easily be verified by medics, such applications are both unnecessarily distressing for patients, at a time when they should be spending quality time with their families and a waste of public money;

The overly simplistic nature of the six-month definition means that patients are not treated with dignity and suffer undue hardship at an extremely difficult time.

Introduction

Launched in 2009, the Brain Tumour Research charity is committed to funding sustainable research into brain tumours. We support one of the UK's largest dedicated groups of laboratory-based scientists, based across our four Centres of Excellence, progressing world-class research into brain tumours to improve treatments, survival rates and quality of life for patients, to ultimately find a cure. We are supported across the UK by numerous Member Charities and Fundraising Groups that have united under our national Brain Tumour Research charity banner. We are also a leading voice in this country calling for greater support and action for research into brain tumours. Brain Tumour Research is also proud to provide the Secretariat to the All-Party Parliamentary Group on Brain Tumours.

<u>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?</u>

Brain Tumour Research believes that the current legal definition is not fit for the purpose of providing timely financial support for those who lack a sufficient income due to them suffering from a terminal illness. It is entirely correct that the welfare system deems those with a terminal illness worthy of speedier access to benefits. However, the six-month legal definition of ‘terminal’ was arbitrary when first introduced in 1990 and, due to advances in medicine meaning those with terminal illnesses survive longer, is now extremely outdated. Due to the varied and complex nature of terminal illnesses, a specific time-limit could never be appropriate to all patients across all medical conditions. For example, just amongst those suffering from brain tumours (of which there are over 130 different types), survivorship after a terminal diagnosis can range from days to decades, depending on the type.

The six-month definition would seem to be based on the disease trajectory of many other diseases, especially the more common cancers, whereby a patient remains relatively healthy and high-functioning for a long-period after diagnosis, before suddenly declining in their last few months.

This is not the case for brain tumours which, as a cancer of the body’s major neurological organ, have a less consistent disease trajectory that can be drawn out over a very long time. Brain tumour patients may either by consistently unwell from before their diagnosis, have noticeable peaks and troughs in their health or just gradually decline over a long period throughout the course of this devastating disease. Therefore, a benefits system that only becomes easily accessible in the final six months will not provide appropriate support to these patients.

Brain Tumour Research would prefer to see reform along the lines of what has happened in Scotland, whereby a temporal definition of ‘terminal’ was replaced by the clinical judgement of a health professional (although this is only applicable to Personal Independence Payment, Disability Living Allowance and Attendance Allowance as control of these benefits has been devolved to the Scottish Government). This means that clinicians, who know their patients and understand their conditions, could make an informed judgment about whether they are ‘terminal’ and thus deserve quicker access to benefits.

In Westminster in 2018, Madeline Moon MP introduced the Access to Welfare (Terminal Illness Definition) Bill4 which would have applied this clinical judgment definition of ‘terminal’ to all benefits across England, Wales and Scotland. Unfortunately, this has not yet progressed beyond First Reading.

It should also be noted that the private sector has a more generous definition of ‘terminal’. Most private insurances that include cover for terminal illness will normally pay out when life expectancy is less than 12 months. Although this is still far from ideal, it is more suitable than the six-month legal definition imposed by the Welfare Reform Act 2012.

Does the six-month definition help or hinder people affected by terminal illness to receive the support they need?

Being defined as ‘terminally ill’ is helpful for applicants as this allows their social security applications to be assessed under the Special Rules for Terminal Illness (SRTI) rather than the general benefits application process. By the end of January 2019, a total of 4,191,000 Personal Independence Payment claims had been registered. Of these, 127,000 (3%) were under STRI5. Adjudication under SRTI has several advantages for applicants:

Once a clinician has returned to the Department for Work & Pensions (DWP) a DS1500 form to confirm the applicant has a terminal condition and a reasonable expectation of fewer than six months life expectancy, the applicant does not require further assessment as to their eligibility for benefits;

They do not have to wait for the three-month qualifying period to get Disability Living Allowance or Personal Independence Payment (PIP), nor wait for the six-month qualifying period to receive Attendance Allowance;

SRTI applicants automatically qualify for the highest and/or enhanced rate of benefits;

SRTI applicants will often receive their first payment within two weeks of applying;

SRTI applicants will receive their benefits weekly in advance.

However, due to the unsuitable and arbitrary six-month definition many brain tumour patients are unfairly excluded from SRTI, which hinders their access to benefits. Those applicants not eligible for special rules are subject to the more arduous benefits application process. Importantly, non-SRTI applicants are subject to both the qualifying periods for benefits and the normal waiting times to actually receive their payments. In the context of suffering an often-debilitating terminal illness, such waiting can be financially crippling (especially as brain tumour patients will normally have their driving licences revoked, which poses another obstacle to earning income). Delays in accessing benefits such as Personal Independence Payment, in turn, lead to hold-ups in associated benefits such as Carers Allowance, tax credits, income support, Employment Support Allowance, housing benefit and council tax discounts.

Non-SRTI applicants also have to undergo a more time-consuming application process, including repeatedly submitting supporting written evidence and attending intrusive in-person assessments to determine their eligibility for benefits.

In written submissions to an Inquiry by the All-Party Parliamentary Group on Brain Tumours6 many patients recounted their distress at having to go through the standard benefits application process in the face of a disease that they knew was terminal:

“To get benefits is difficult and then made worse by the following reassessments to try and keep them. Having to go over and over again that my daughter will never get any better…” Mother of a brain tumour patient, West Yorkshire

“The fact that my brother was forced to work full-time literally up until the day he died is something I find utterly sickening. As a father of two young children battled through the treatment and trauma of brain cancer while also working 10 hours a day.” - Brother of a brain tumour patient, Leicestershire

“One thing I have become increasingly frustrated with is the number of forms and evidence required to support each application. I understand a robust process is required however there is only so many ‘original’ copies of evidence I can supply to each individual organisation and every time my GP/specialist is contacted and asked to fill out a form as well. I find myself apologising to the GP/consultant as not only do I find it a waste of my time but more importantly a significant waste of their valuable time” - Brain tumour patient. London

In light of the above, it is unsurprising that a recent survey of brain tumour patients found that, per year, they only receive an average of £4,7677 of benefits. These same patients face a significant loss of income8 and a living/travel (for treatment) cost increase of £3,7029. The small amount of financial support received whilst suffering from this uniquely devastating cancer, is one reason why households with a brain tumour patient are on average £14,78310 per annum worse off.

The Government itself has claimed that the six-month rule is not absolute, which could be taken as a tacit admission that the rule is an unnecessary hindrance. The current six-month definition for the purposes of applying for benefits is certainly not suitable for complex conditions such as brain tumours. The crudity of the definition runs the risk of individual circumstances being ignored, which, to quote the APPGTI’s Chair, Drew Hendry MP, leads to those suffering from terminal illness being treated as numbers on a spreadsheet, rather than people.

22. Dignity in Dying

Dignity in Dying campaigns for greater choice, control and access to services at the end of life. We advocate providing terminally ill adults with the option of an assisted death, within strict legal safeguards, and for universal access to high quality end-of-life care. ‘Terminally ill’ is defined in our proposed law as having an irreversible and inevitably progressive condition, in which death can be reasonably expected within six months. The assessment of prognosis would be made by two doctors, acting independently of each other and in good faith.

The largest poll ever conducted on the issue of assisted dying in Britain recently found that 84% of adults support a change in the law. As this very high level of support suggests, Dignity in Dying has hundreds of thousands of supporters across the country. Many support the campaign due to their own experience of living with a terminal illness or of caring for a dying loved one.

Our response to this inquiry is therefore primarily based on evidence of our supporters' views and experiences of the Special Rules on Terminal Illness (SRTI).

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?

For the purposes of gaining fast-track access to benefits, Dignity in Dying supports changing the legal definition of terminal illness.

We support the proposed change as we believe it would meet the need for financial support relatively early in the progression of a terminal illness. We agree with the APPG on Terminal Illness' assessment that: "Due to advances in treatment people are now terminally ill for longer, and do not fulfil the six-month life expectancy criteria at the point that they begin to need financial support."

Our position is based on our commitment to terminally ill people having the best possible care and support before they die, and on what we have learned from our supporters, many of whom have direct experience of the applying for benefits under the SRTI.

Dignity in Dying sent a short survey to some of our supporters asking for their views and experiences on the issues raised in this Inquiry. We received responses from over 1,200 people. Of these people, 9% are themselves living with a terminal illness, 3% are living with a chronic illness, 64% either are or have been a carer for someone with a terminal illness and 4% of respondents are healthcare professionals. 24% of respondents said that either they or the person they care for had accessed benefits under the existing SRTI.

In response to the question 'Do you think the rule for a terminally person having fast-track access to benefits should be changed from having six months left to live, to a doctor's clinical judgement that they are terminally ill?' 88% answered yes, 9% said they were unsure and just 1% answered no.

Many of our supporters described their personal experience of why the inclusion of the six month prognosis is not fit for purpose in the context of SRTI in claiming benefits. The key points raised by respondents to our survey are summarised in the bullet points below and illustrated by the quotes that follow:

Some terminal illnesses mean the person is unable to work long before they have a prognosis of six months, putting the dying person and their carers and family under increased financial and emotional pressure:

My husband, who has now died was diagnosed with advanced bowel cancer. He attempted several times to obtain PIP (Personal Independence Payment) but was denied it. He was unable to work for over 18 months because of the treatment, surgeries, and the fatigue *caused by chemotherapy. He was only granted PIP once the oncologist changed his prognosis to terminal. My husband was constantly worried that we wouldn't have enough money and returned to work even though he was not well enough to do so and was in constant pain. He was eventually granted full benefits six months before he died. I now have stage 4 cancer myself. I haven't even attempted accessing the benefits system because I am scared and anxious that I will be turned down, based on my husband's experience. (Former carer who now has cancer herself)*

Six months is an arbitrary figure - as people are unable to work it causes problems. (Carer)

Many respondents commented on the financial and employment implications for carers and family members as well as the dying person:

Living with a terminal illness has a lot of implications. Often one is too poorly to earn a decent income and if you have a partner or someone else caring for you it can affect their income too. There are often a lot of unforeseen expenses associated with serious illness. (Person with a terminal illness)

I ended up giving up work to look after my mother in her final months. It would have helped us both if she could have accessed benefits earlier in her illness – that money could have gone towards getting extra support at home for her which would have helped me too. (Carer)

Carers and people with terminal illness commented on the hidden costs of being ill. These comments were accompanied by a strong belief that the SRTI should start much earlier to help support these costs:

Once the terminal diagnosis is given, life for the patient and all involved changes for ever in the most appalling way. The additional financial costs involved e.g. travel to multiple hospital appointments, extra heating and care costs should be alleviated as quickly as possible by early access and advice to benefits. (Carer)

Being ill is expensive - lots of hospital trips - petrol, parking. Increased heating costs due to being cold due to weight loss and hair loss from chemo. (Carer)

People put forward a number of reasons as to why SRTI starting earlier would be beneficial:

My husband has cancer which is treatable but unfortunately incurable and is now unable to work - his previous employer terminated his job two months after his diagnosis. He should only have to worry about his treatment, not how to get a job when he is having chemo twice a week for next two and half years. (Carer)

I have both upper and lower motor neurone lesions and at the moment I have severe muscle wastage and have severe mobility issues and year on year need more assistance to carry out the tasks everyone else does without thought. I am also in constant severe pain. I am now really frail and will soon end up in a position where life becomes more than difficult. I am *in receipt of PIP and fortunately my claim went through without any problems and quickly too.*

People like me have enough stress in our lives due to financial worries and the Government should overhaul the current system which, for many sick people, acts more like a disability denial system than one which should be providing them with sufficient funds to live out their final days in the best circumstances possible. (Person with a terminal illness)

I have been living with incurable lung cancer but have only just been able to make a claim now that I'm terminal. It would've been more useful to me before becoming so ill. (Person with terminal illness)

This is surely obvious that the fast track access to benefits should happen earlier. If you are poor or live alone - as I do - this extra help is vital. (Person with a terminal illness)

Comments from healthcare professionals reflected many of the concerns of carers and terminally ill people:

If a person has an illness that is so serious and they can't work they need financial help straight away! (Care worker)

This is a harsh rule that can lead to hardship for those with a severe terminal illness, who may need access to benefits before the 6 month deadline. (GP)

Someone with end stage Parkinson's or dementia or motor neurone disease can be declining rapidly but have over 6 months to live, and they and their carers should be entitled to benefits to help them in any way possible. (Palliative care community nurse)

I have met too many people, individuals, couples, families, who got into unnecessary financial problems as a direct consequence of the illness or of the fact that they had to care for their ill loved one. (Hospice worker)

I think doctors can be fearful about giving a person a prognosis of less than 6 months so people aren't identified and referred for fast track support. The fast track application process and the hospital's ability to source care to support fast track discharges from hospital are not quick! We're often too late in getting the right support to these patients. (Occupational therapist)

A small number of respondents suggested changing the prognosis requirement from six months but not necessarily moving to the clinical judgment definition used in Scotland:

Terminal illness needs to be defined more clearly even if the six months is dropped. (Carer)

I think it depends on the individual's needs and everyone should be assessed on their own circumstances. Someone could have a terminal illness but live without pain or the need for regular home visits etc. Whereas someone else could be in excruciating pain for 12 months *and need the necessary assistance and care to make their time left on earth more comfortable. (Carer)*

I think it would be reasonable to move the prognosis definition to 12 months as increased benefits could be a great help to families before the situation gets too dire. Where the prognosis is more than one year it can often be hard to be sure of the life expectancy. (GP)

The overwhelming message from our supporters, which we endorse, is that the current definition of terminal illness is not fit for purpose in regard to fast track access to benefits.

For the avoidance of doubt, Dignity in Dying's position is that a definition of terminal illness based on a six month prognosis would be appropriate for other purposes, such as access to assisted dying (should the law change on that issue).

For example, in Australia, a person with a terminal illness can access relevant benefits and the ability to take out pensions when they have a prognosis of 24 months. Alongside these rules, the assisted dying law in Victoria, Australia, which will come into effect on 19 June, will only be available to those with a prognosis of six months or less (or 12 months or less for those with neurodegenerative condition).

Coincidentally, one of the supporters who responded to our survey holds dual citizenship with Australia, and commented on the system of access to benefits at 24 months that operates there:

I was diagnosed with stage 4 cancer approximately a year ago. I am a dual British citizen with Australia, I accessed the full payment from my private Australian pension. The fast track access is available for terminally ill people with an estimated 12 to 24 months life expectancy. I had to supply evidence from two qualified health professionals.

I believe all terminally ill persons here in the UK should have the choice to access benefits at a much earlier stage. These funds are essential to enable a decent quality of life for their remaining lifetime. (Person with a terminal illness)

Differentiating the prognosis requirements for definitions of terminal illness for different purposes clearly makes sense. Financial support is obviously needed much earlier in an illness to support someone to live well and with the right care support, while the option of an assisted death is for people at the very end of life who want the peace of mind of knowing they can control their imminent death, should their suffering become unbearable.

<u>Does the six month definition help or hinder people affected by terminal illness to receive the support that they need?</u>

Some of our supporters reported good experiences with the SRTI, though these were not specifically tied to the six month definition:

My wife had DLA (Disability Living Allowance) at full rate when a PIP form was sent. I rang up DWP (Department of Work and Pensions) and her claim was taken over the phone. I *contacted GP to send the required forms. I received a phone call from DWP to say full payment would be made. My wife received her subsequent notice of entitlement to PIP within 2 weeks. I was very impressed. All members of staff I have spoken to at PIP have been kind, caring and ultra-efficient. (Carer)*

I have MND. When I was first diagnosed three years ago I applied for PIP under special rules. My application was successful. Since then my health has continued to deteriorate, I become more and more disabled each day. The benefits are needed, and I'm relieved I got them at an earlier stage. (Person with motor neurone disease)

We were advised to apply for Attendance Allowance under the special rules as MND is so unpredictable, and can progress so fast. My MND Care Centre sent a DS1500 and I was granted Attendance Allowance at the higher rate without fuss. It was a great relief. (Person with motor neurone disease)

However common themes were the need for support to complete the form, and lack of awareness that they could even apply:

Being diagnosed with a terminal illness is stressful enough, being unable to work, the benefit minefield for many the first time they have claimed, the worry of not answering a question correctly and being denied vital cash. If this wasn't bad enough then there's the assessment and waiting months to see if you qualify. (Person with a terminal illness)

The person I was caring for was diagnosed with a terminal illness after being found unconscious at home. MacMillan helped me to identify and apply for the relevant benefits. The person died 4 weeks later and payment was finally received about 4 months after the person died. I am very on top of paperwork and technology but every step of the way after MacMillan's initial help was extremely difficult and fraught with constant problems and red tape. It was an incredibly difficult and emotional time and most people would have given up, but I kept pursuing it because it was owed. The patient certainly didn't benefit from such financial help during her lifetime. It is an appallingly difficult and obstreperous system and needs a serious radical overhaul. (Carer)

My mother was in a hospice, and moved to a nursing home unfortunately without assessment for terminal living allowance. She should have been assessed in the hospice, but wasn't assessed until she had been in the home for 3 months. In my mother's case it would have been easier for all of us if we had more time to set up benefits for her. (Carer)

My husband was very fit. Then he had blood tests, X-rays and scans showing that advanced prostate cancer had spread to his bones and he was declared 'terminal'.

We were in total shock, had no experience of the benefit system and at no time did the GP or hospital staff advise us to seek help to claim. We accept that medics have enough to do without personally getting involved, but on reflection as soon as a person is given a terminal diagnosis it would seem appropriate for them to be given a leaflet with the relevant benefit information and the nearest Welfare Rights advice centre.

In our case it was only when a person visited from the Hospice that we knew to claim for Attendance Allowance. By that time we had missed months of payments, which could have helped with transport costs, which took a large part of our state pensions. It was also helpful to get a Blue Badge. (Carer)

My husband was told in January that he had terminal cancer, we were not told about possible benefits available to us until roughly two weeks before he died. Therefore, we were unable to access any benefits. (Carer)

The six month prognosis causes stress in several ways. People who do qualify for the SRTI may be concerned that if they outlive their prognosis they will be reassessed for benefits:

What happens if you live longer than the expected 6 months, will the person be penalised for surviving the illness longer than expected. They are, however, still terminally ill. (Patient with lung cancer, receiving benefits)

I was diagnosed with my terminal illness in April 2015. I have intestinal failure as well as other serious organ problems. I recently accessed SRTI benefits but I am so anxious because the nurse who did my assessment said I should be reviewed in 18 months time if I am still alive. Just because someone might live more than 6 months, does not mean they are necessarily capable of living a normal life and being able to deal with the extra stress of being assessed again. (Person with a terminal illness)

People with terminal illness are left distraught when they are told that they do not qualify:

When you are diagnosed as terminally ill, you want as long as possible. To be told you don't meet the criteria (when in my case I have 35 years full national insurance contributions that I'm never going to see) is a slap in the face and highway robbery as far as I am concerned. (Person with cervical cancer)

I should not have to worry about trying to fight and feel guilty for applying for benefits when I am struggling with chemo that is bad enough. (Person with a terminal illness)

People often don't access the benefits under SRTI until very near (or even after) they die:

My Mum received the benefits under SRTI 4 months before she died. My Mum could have used the benefits to have a better quality of life in her last year. We knew that her condition was terminal and by the time she accessed the benefits she was too poorly for them to be the maximum help to her. If she had been able to access them sooner it would have taken away some of the financial worry at an already difficult time. (Carer)

My mum was only given a few short weeks but she did receive a small benefit and blue badge after I collected paperwork from her own GP stating she had stage 4 cancer and was terminal. It would have been great if it just kicked in automatically without having to run about and ring around. Life changes drastically with a terminal diagnosis and worrying about money shouldn't be added to the scenario. (Carer)

Making ends meet was very difficult for my mother because dad was ill for so long but the "terminal illness" prognosis came too late for us to make any claims for help for her. (Carer)

My wife was ill for over 3 years with MND. We effectively lost everything we ever worked for and I am now left with debts of over £20,000. And I couldn't even get a bereavement grant!! (Carer)

My late husband had Leukaemia and Lymphoma. No longer well enough to have Chemo his only chance was a stem cell transplantation. Because we didn't know if this was going to work or how long he would live we were unable to apply for benefits. Sadly he didn't live long enough to have the transplant. If we had received some financial help and a blue badge it would have helped so much as I had to cope with being his full time carer and working full time. It destroyed me. (Carer)

Healthcare professionals also gave examples of how the six month requirement does not help patients:

The decision to fast track is often delayed. This can be because the patient doesn't accept or fully comprehend their diagnosis or in some cases doesn't want to know their prognosis so has not specifically asked and their specialist has therefore not given a prognosis. Doctors sometimes delay fast tracking because they are worried the prognosis maybe wrong (even though there are no consequences to fast tracking in these cases) or do not want to discuss the prognosis with an otherwise hopeful patient. These are a few of the many barriers the need for a 6 month prognosis puts in the way of good care. (GP)

I've supported many patients with applications for special rules benefits. They were sometimes denied but I successfully challenged these decisions on a number of occasions. (Palliative care social worker)

23. Parkinson's UK

Every hour, two people in the UK are told they have Parkinson's - a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

About Parkinson's

Parkinson's affects about 145,000 people in the UK. While the majority of people develop symptoms after the age of 65, thousands of working age people are also affected.

Parkinson's is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, swallowing and writing. People with Parkinson's often find it hard to move freely. There are also other issues such as pain, depression, dementia, hallucinations, and continence problems. The severity of symptoms can fluctuate from day to day and people can experience rapid changes in functionality in the course of the day. There is no cure.

Overview

Parkinson's UK is delighted to have the opportunity to contribute to this important Inquiry.

Parkinson's is the second most common neuroprogressive condition after Alzheimer's, with an estimated population of 145,000 people in the UK. Parkinson's UK believes that people with Parkinson's should be signposted to the disability benefits system at an early stage of the condition, and we are working to make sure that this happens though our comprehensive information and support service, including expert benefits and employment advisers, our community-based local adviser team, website and printed information. If people with Parkinson's claim benefits at an early stage, they will do this under the standard system.

Progression in Parkinson's is variable, but it is common for people to live for a long time with impairments that would entitle them to receive disability benefits at the highest rates. Research from the North East of Scotland shows that after five years with Parkinson's, about half of people need help with basic tasks like washing and dressing, and after ten years almost everybody does.

However, we know that – for a number of reasons - some people with Parkinson's do not attempt to claim the benefits to which they are entitled until their condition is very advanced. In other cases, people are not signposted to the benefits system until they reach this point. For some people, Parkinson's progresses more quickly than is usual. Finally, some people who are initially thought to have Parkinson's are later found to have atypical Parkinsonisms such as Progressive Supranuclear Palsy (PSP) or Multiple System Atrophy (MSA), which are considered to be terminal. Both conditions progress very rapidly, and MSA carries a very high risk of sudden death. There are an estimated 3,000 people in the UK with MSA and 4,000 with PSP, which compares with around 5,000 people with Motor Neurone Disease (MND).

Accessing benefits under special rules can make a huge difference for people whose condition is progressing very rapidly, because the qualifying periods for applying under the normal rules (three months for PIP and six months for Attendance Allowance) introduce further delays in accessing benefits for people whose time is limited.

Parkinson's UK welcomes the opportunity for more people in these situations to access disability benefits under special rules. We supported the change in the qualification criteria for special rules in relation to devolved benefits in Scotland, where the decision will now be made on the basis of clinical judgement that a person "has a progressive disease that can reasonably be expected to cause the individual's death".

We believe that a change in the legal definition for benefits that are reserved to Westminster is also needed.

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?

Parkinson’s UK does not believe that the current legal definition is fit for purpose. Making an accurate prognosis in terms of a specified number of months of life can be very challenging in any situation, but it is particularly difficult when people are reaching the end of their life with a non-malignant condition.

Parkinson’s is progressive and incurable, with no treatment that can slow or stop its progression. While some people can live for two decades or more after receiving a Parkinson’s diagnosis, this is not the case for the overwhelming majority of people with Parkinson’s.

In common with other neuroprogressive conditions, people with Parkinson’s typically follow a trajectory of prolonged dwindling and increasing frailty, rather than the more sudden and rapid decline often seen in the end stages of conditions like cancer. The frailty trajectory is unpredictable, and prognostication can be extremely difficult.

About one in seven people with Parkinson’s is estimated to be in the so-called palliative stage of the condition. This stage of very advanced Parkinson’s is marked by severe motor symptoms which may leave people with very limited movement and complex non-motor symptoms affecting speech, swallowing and continence. Mental health issues including dementia are common. People require very high levels of care and support. However, the length of time that the palliative stage lasts is very variable – on average it is just over two years, but it may be much longer or shorter than this.

There is other evidence that suggests that clinicians are very poor at identifying that people with Parkinson’s are reaching the end of life. People with advanced Parkinson’s have quality of life as bad as – and in some cases worse than - those with terminal cancer and MND. Yet people with Parkinson’s much less likely to have been involved in advance care planning, or to have received specialist palliative care input than those with other types of condition. This reflects wider work showing that people with non-malignant conditions are very unlikely to received specialist palliative care input at all, such as work by Audit Scotland and Marie Curie.

If clinicians are required to certify – with certainty – that people have six months or less to live to access benefits under special rules, they are unlikely to do so when the person has Parkinson’s or other neurological conditions that follow a similar pattern of decline. This means that people are unable to access benefits under special rules, and must go through the stress, complexity and time of applying for much-needed benefits via the conventional system at a time when they are extremely unwell.

Does the six month definition help or hinder people affected by terminal illness to receive the support that they need?

Parkinson’s UK believes that the six-month definition hinders people affected by terminal illness from receiving the support that they need.

Getting access to benefits can make a huge difference to household income at a time when life is very challenging and extra costs can be incurred. In addition to the disability benefit itself, there are passported benefits such as pension credit, housing benefit and council tax support as well as access to benefits to support unpaid carers such as Carers Allowance, carers credit. In addition, the ability for payments to be backdated and the fact that qualifying periods are not needed can increase the value of an award considerably.

It is important to consider that the support offered under special rules is not just financial. For people with Parkinson’s aged under 65, a PIP award under special rules is very likely to include high rate mobility, which will enable them to access an adapted vehicle via the Motability scheme and a blue badge. These make an enormous difference to quality of life and enables people with advanced illness and significant impairments to continue to participate in their community, and access locations outside their home. This may be impossible without an adapted vehicle and the ability to access disabled parking facilities.

In addition, for people who are very unwell with advanced Parkinson’s, it may be very difficult or even impossible to meet the obligations associated with receiving benefits under normal rules. These include attending a face-to-face assessment, or undertaking work-related activities. Accessing benefits under special rules removes these obligations, enabling people with advanced illness and deteriorating health to access the support they need without worrying about needing to meet these obligations or being penalised.

We would like to highlight that there are particular issues for people in Scotland who need to access benefits that are reserved to Westminster as well as those that are devolved to Scotland. Scottish Government has confirmed that a DWP DS1500 form will be accepted as proof of eligibility for devolved benefits under special rules, but there is no suggestion that a completed Scottish form will be accepted as proof of eligibility for reserved benefits under special rules.

The consequence of this is that a person who is eligible for PIP in Scotland under special rules but who also needs to access Universal Credit (UC) or Employment Support Allowance (ESA) will have to meet the current DWP definition to receive UC or ESA under DWP special rules. We note that people who require income replacement benefits in addition to non-means tested disability benefits are likely to be among those claimants facing greatest hardship if they cannot access their full entitlement quickly.

If their clinician is not prepared to certify that the person has six months left to live, the person will face the stress and time delay of going through the standard system to receive the rest of the benefits to which they ought to be entitled. Another potential risk is that these individuals will not pursue their special rules PIP entitlement unless they are able to qualify under DWP rules. This could leave people without support to which they are entitled at the most difficult time.

Conclusion

Parkinson's UK does not believe that the current legal definition is fit for purpose. Making an accurate prognosis in terms of a specified number of months of life can be very challenging in any situation, but it is particularly difficult when people are reaching the end of their life with a non-malignant condition.

Parkinson's UK believes that the six-month definition hinders people affected by terminal illness from receiving the support that they need, including financial and other forms of assistance.

Parkinson's UK recommends that the UK Government changes the law to remove the six month prognosis requirement to access disability benefits under special rules. As in Scotland, we recommend that the guidance should depend on a clinical judgement that a person's health is deteriorating and likely to result in the person's death with no time limit required.

For the purpose of gaining fast track access to benefits, is the current legal definition of being terminally ill as having six months to live fit for purpose?

24. Tenovus Cancer Care

Tenovus Cancer Care is Wales' leading cancer charity. Our aims are simple. We want to help prevent, treat and find a cure for cancer. We do this by offering support, advice and treatment to cancer patients and their loved ones. We also promote healthy lifestyles and fund cancer research to find new ways to prevent it, diagnose it, and treat it.

We welcome the opportunity to respond to this important consultation.

The sudden and unexpected loss of income, coupled with hidden costs, the worry, and stress of financial pressure that accompanies a cancer diagnosis all place a huge burden on people. Tenovus Cancer Care recognises this; that's why our skilled Cancer Support Advisors are on hand to tell people affected by cancer if there's any money they might be entitled to. So when cancer patients or their loved ones have money on their mind, they have someone to talk to. When someone is nearing the end of their life for a known reason the magnitude of these pressures are amplified significantly.

The complex warren of the benefit application process is difficult enough under normal circumstances, let alone during this period of heightened distress. The existence of a fast-track process for people with terminal illness is very helpful. It relieves pressure from individuals and their families at a time when priorities will be focussed on the time that remains; not red tape and a system that is not known for its user friendly credentials.

However there is a common misconception regarding the six month rule. Many interpret it as someone having less than 6 months left to live. This neglects the important part of the rule that if it would not be unexpected for them to pass away within 6 months. It is difficult to put a precise end date on someone's life; particularly in light of medical advances and the management of terminal diseases. In reality few clients receive a prognosis of less than 6 months, with many receiving a prognosis in excess of 9 or even 18 months. Some consultants are still willing to complete the DS1500 form (DWP form that confirms terminal illness) but some are very stringent.

Therefore, Tenovus Cancer Care support the fast-track process for access to benefits however we call for the 'six month rule' to be scrapped in favour of a revised definition that classifies anyone as terminally ill if they diagnosed with a progressively degenerative disease where death is an expected consequence.

25. Together for Short Lives

Together for Short Lives is the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children's palliative care sector – so that no family is left behind.

We support all the professionals, children's palliative care services and children's hospices that deliver lifeline care. We have over 1,000 members, including children hospices, voluntary sector organisations and statutory service providers. By working together, we provide a strong and unified voice for the sector, and help services deliver the best quality care and support tailored to each family's needs.

Our submission to the inquiry focusses on the challenges and experiences faced by babies, children and young children with life-limiting and life-threatening conditions, and their families.

Although children diagnosed with a life-limiting or life-threatening condition may be expected to only live for a matter of weeks, months or years, the term 'terminally ill' is rarely used in paediatrics.

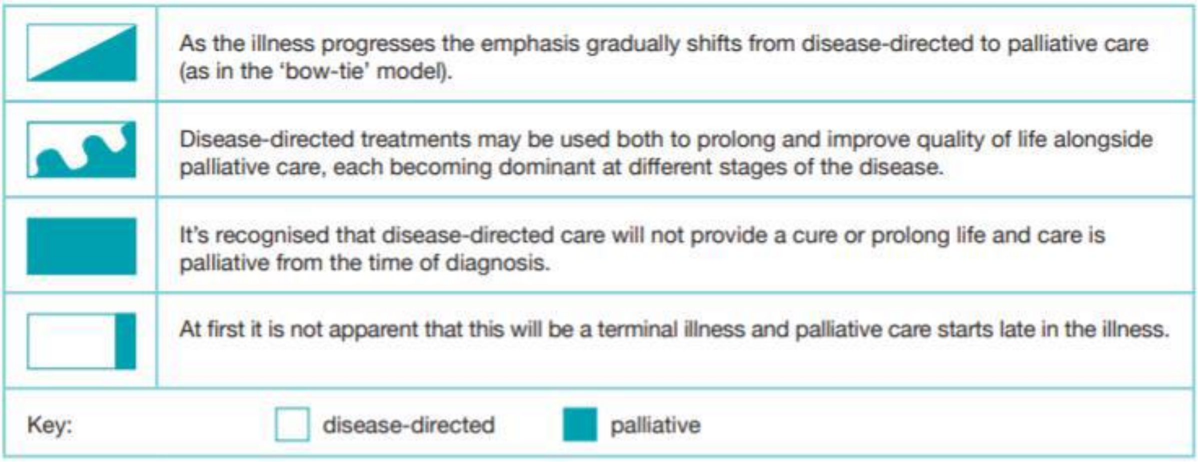
We believe that the current legal definition of being terminally ill is unsuitable and obstructs children with life-limiting or life-threatening conditions from accessing financial support in a timely manner at the point they and their families most need it. We ask that the definition adopted by the Scottish Government, which allows fast-tracked benefit access without the requirement of a time-limit, should be similarly introduced in the rest of the UK.

<u>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?</u>

Thanks to changes in medicine and clinical support, children with life-limiting and life-threatening conditions are living longer. However, conditions are still unpredictable and can worsen suddenly and unexpectedly.

It is important to acknowledge that following diagnosis or recognition, the trajectory of a child's illness or condition is unpredictable. Irreversible but non-progressive conditions causing severe disabilities can put children at a high risk of an unpredictable life-threatening event or episode, but may not fall within the current legal definition of a terminal illness.

The chart below (Fig. 1) depicts some of the trajectories that children with life-threatening or life-limiting conditions may experience. Throughout their lives the expectations of their health may shift and may improve or deteriorate rapidly and unexpectedly.



	As the illness progresses the emphasis gradually shifts from disease-directed to palliative care (as in the 'bow-tie' model).
	Disease-directed treatments may be used both to prolong and improve quality of life alongside palliative care, each becoming dominant at different stages of the disease.
	It's recognised that disease-directed care will not provide a cure or prolong life and care is palliative from the time of diagnosis.
	At first it is not apparent that this will be a terminal illness and palliative care starts late in the illness.
Key:	☐ disease-directed ■ palliative

Children with life-limiting or life-threatening conditions are likely to have a number of periods in which their health deteriorates, followed by a recovery. It is important that the variability and unpredictability of these conditions is recognised in the legal definition of terminal illness, as related to access to fast-track access to benefits, so that no families are left behind. A definition which includes a time-limit is therefore not appropriate for children.

Together for Short Lives supports the recent decision by the Scottish Government to remove any time-restriction from disability assistance applicants with a terminal illness. Under the Social Security (Scotland) Act 2018, the definition of terminal illness for the purpose of disability assistance will be based on the clinical judgement of a registered medical professional, removing any time restriction.

This clinical judgment will be based on guidance to be issued by the chief medical officer (CMO) and will enable registered medical practitioners to make a clinical judgement about whether an illness is regarded as terminal, for the purpose of accessing disability assistance.

Together for Short Lives would like to see a similar definition adopted in the rest of the UK so that families of children with life-limiting or life-threatening conditions are able to access crucial financial support. We recognise that guidance on the definition would need to be issued and would welcome the opportunity to respond to a consultation on the details of this.

Removing this time restriction will help protect families from building a ‘debt legacy’ when trying to meet the extra costs associated with care and would recognise the immediate financial pressures that families find themselves facing.

Does the six month definition help or hinder people affected by terminal illness to receive the support that they need?

The extra costs and financial pressures faced by families caring for children with life-limiting or life-threatening conditions is significant, regardless of how long that child is expected to live.

Contact’s 2018 ‘Counting the Costs’ survey found that families who provide long-term care for a disabled child face huge financial difficulties. This survey showed that in the past year, over a third of families have extra disability and care related costs of £300 or more per month. They also found that 7% of families had taken out more than five loans in the past year and that almost half (46%) the families had been threatened with court action for not paying bills.

This is partly explained by the fact that 87% of families reported having caring responsibilities that mean they are unable to work as much as they would like.

Additionally, the survey found that:

- 26% of parents said their child’s condition has worsened due to going without basics
- 33% have taken out a loan to pay for food
- 26% of disabled children are going without essential therapies.

Delayed access to benefits and financial support is intolerable for any of these families, regardless of how long children are expected to live, and can contribute to a debt legacy which may remain for years following the death of a child.

Recommendations

Together for Short Lives would like the definition of a terminal illness – for the sake of benefit applications – to be changed from “a progressive disease and their death as a consequence of that disease can be reasonably expected within six months” to one which is based on the clinical judgement of a registered medical professional – and which does not include a time limit.

Together for Short Lives would welcome an opportunity to work with the Department of Health and Social Care and the Department for Work and Pensions to help shape any guidance which is developed to help clinicians determine whether a child or young person is terminally ill.

26. St Christopher's

St Christopher's welcomes the All Party Parliamentary Group on Terminal Illness's interest on the legal definition of terminal illness for benefit claims and would welcome any moves to change the rules to remove the 6-month time limit from the definition. We believe that the time limit is anomalous to current palliative care and would welcome proposals instead to make it subject to clinical judgement in line with Scottish law.

St Christopher's Hospice provides support to more than 3,500 people a year living with a terminal illness in the diverse London communities of Lambeth, Southwark, Lewisham, Croydon and Bromley. This includes people living with terminal illness in the community and those in need of admission into our inpatient unit and their families and carers. Our services for families and carers extend into bereavement. Our vision is of a world in which all dying people and those close to them have access to the care and support they need, when and wherever they need it.

It is difficult to underestimate the devastating social, emotional and financial effects of a terminal illness and an essential element of hospice care includes services to help support patients and families as well as specialist palliative medical and nursing care. At St Christopher's this includes support from specialist services such as social work, therapists, spiritual care and a welfare service.

We do not audit the number of DS1500 forms issued through the Hospice but supporting patients to claim benefits they are entitled to as a result of their illness is an embedded part of the help we provide. The fast-track access to these benefits for our patients is invaluable.

The impact of being diagnosed with a serious illness can be devastating and far reaching. Life can be quickly thrown into disarray and dealing with the consequences can be very difficult. Those of us who are fairly fit may find it difficult to understand that even attending hospital appointments for treatment is barely manageable if, for example, you are fatigued, constantly nauseous or you have significant pain. Dealing with daily life, the needs of the family, bills, employers and everything else can soon become overwhelming. It is not surprising; therefore, that dealing with a clunky and opaque benefits system to get what may be essential basic financial support can feel impossible.

Welfare reform has meant that the barriers to successful benefit claims are more onerous and difficult to overcome. For example, benefit claims have to be made in a specific way, with all relevant documentation. In general they involve multiple assessments which mean completing long forms and attending face to face assessments. Where multiple benefit claims are required this process has to be done separately for each benefit. Fast-track access helps to ease this burden and can make the process easier to manage. This in turn helps to make life a little easier. Furthermore, fast-track access makes the delivery of benefits more efficient when entitlement is obvious.

The 6 month definition is not yet a barrier to issuing DS1500 forms for the majority of patients referred to St Christopher's. In general, prognosis is poor by the time a referral is made. However, changes in palliative care and medical research have begun to make this less of a certainty. Clinical staff are reporting that trying to ascertain prognosis is taking up more and more of their time.

It is common now for patients to be enrolled in medical trials and in most cases being entered on to a clinical trial is the result of other curative treatment having been unsuccessful. Clinicians can be placed in a conflicting position if they are being positive about a trial treatment on the one hand yet signing a document indicating a 6 months prognosis and therefore that it is likely to fail on the other.

In addition, improvements in medical treatment generally has meant that patients referred to the Hospice are more likely to present with comorbidities which can lead to a complex web of chronic conditions as well as the illness with the terminal diagnosis. It is sometimes impossible to predict how these will all interact when considering a prognosis and sometimes it is the interaction that causes early death rather than any one condition.

Palliative care in the UK is changing. When the modern palliative care movement was starting there was a concentration on patients with a cancer diagnosis. The legacy of that still lives with us but it has long been recognised that palliative care is appropriate for many other conditions and the hospice movement has made great strides extending its care to many conditions such as motor neurone disease, heart disease, chronic lung conditions, kidney disease, Parkinson's disease or dementia. The issue here is that prognosis is harder to estimate and trying to predict when someone is within the last 6 months of life is more difficult. Patients can plateau for years with an expectation that a catastrophic event can occur at any time.

Hospice care is changing too. It has traditionally focussed on managing symptoms and supporting people to live as fully as possible with their illness, but now there is a greater emphasis on rehabilitative care and an understanding that even though a disease is progressing it is possible to improve symptom load and prognosis with good palliative care. This adds to the difficulties with a 6 month definition. It does not fit with an expectation that good palliative care will improve life expectancy without changing the facts of a progressing disease.

Another way that hospice care is changing is that there is an increasing recognition that the provision of palliative care could be improved with certain marginal and deprived groups, such as the homeless and within institutions such as care homes and prisons. It is more likely that these groups of people will have complex care needs and that there will be difficulties with diagnosis and prognosis. It is very likely that these groups have even more need for benefit support where entitled and will usually have less ability to access them through the usual routes. It is these groups who probably lose out the most under the current 6 month rules.

In conclusion, we are finding that it is increasingly incongruent to define terminal illness with a time limit. The diagnosis of a terminal illness means that people are deprived of hope that there is any chance of returning to a normal life and that the progression of the illness is inevitable. The chaos this brings to all parts of life is hard enough to cope with. This should be enough to enable fast access to the financial help that is often desperately needed. Emphasising that necessary help is only fully available once you have only a few months to live leads to hardship for the patient and families and extra inefficiency in the benefits system making unnecessary assessments. We believe that there are safeguards already in the system with the limiting of special rules claim to three years and believe that it is reasonable to re-examine entitlement at that point.

27. The SDLP

The SDLP welcomes the opportunity to submit evidence to the APPG on this important issue affecting so many people across Northern Ireland. We are deeply frustrated that due to the ongoing standoff between the DUP and Sinn Féin, we are now into the third year of having no devolved Government and Assembly in Northern Ireland to conduct a critical inquiry of this nature. It is reprehensible that people who are dying in Northern Ireland continue to be denied a devolved government to make representations to, and to act in their best interests.

The evidence we are submitting to this Inquiry under the questions posed by the APPG is drawn from, and based, on the constituency service provided by our extensive team of elected representatives and activists across Northern Ireland, our advocacy work for the terminally ill and our close engagement with claimants affected by terminal illness, their families, carers, the advice sector, charities, medical profession, academics, and other political parties on the issue of fast-track access to social security payments like Personal Independent Payments (PIP), Universal Credit (UC) and Employment and Support Allowance (ESA) under Special Rules for Terminal Illness.

For the purposes 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?

In short no. Medical understanding and treatments have changed significantly since the introduction of this definition into legislation in 1990. This definition has not kept pace with this change and is not fit for purpose. This was highlighted in an open letter signed in June 2018 by 60 clinicians, academics and other experts in health and social care across Northern Ireland. In this letter they stated: the current six month “restriction is unfairly excluding many people with terminal illnesses”.

“Many other terminal illnesses have more unpredictable trajectories and life expectancy is harder to predict accurately. Many terminally ill people, including those with Motor Neuron Disease, Chronic Heart Failure and COPD, fail to access PIP under special rules, meaning they have to wait much longer for their payments and undergo face-to-face assessments. This is unfair and denies people the best quality of life during the time they have left”.

"The Scottish Government has adopted a definition of terminal illness based on clinical judgment, rather than a time-bound estimation of life expectancy. We believe the situation should also be reviewed in Northern Ireland with a view to aligning with the Scottish approach. This compassionate model will allow many more people with terminal illnesses to get the help they need when they need it".

The SDLP completely agrees with this assessment. (A full copy of this letter with all signatories is provided in Annex A).

The case for change was also recommended in An Independent Review of the PIP Assessment Process in Northern Ireland commissioned by the Department for Communities and carried out by Walter Radar. The findings of this report, published in June 2018, contain a recommendation to remove the arbitrary six month life expectancy used as the threshold for accessing the fast tracked PIP Assessment process.

Recommendation 6: "That the clinical judgment of a medical practitioner, indicating that the claimant has a terminal illness, should be sufficient to allow special rules to apply. The 6 months life expectancy criterion should be removed". The full report can be accessed via this link: https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-independent-review-pip-assessment-process-june-2018.pdf

The SDLP submitted evidence making the case for this change to Walter Radar. It is a recommendation we have been campaigning for and wholeheartedly endorse. No one affected by a terminal illness should spend the precious time they have left going through the arduous and distressing PIP application process with its intrusive face-to-face assessment and then left to wait for up to three months on a decision.

The conclusion that the current definition is not fit for purpose is also the collective and unanimous view of all of the main political parties in Northern Ireland. Under an initiative led by the SDLP, an all-party letter, signed by the SDLP, DUP, Sinn Fein, UUP, Alliance and Green Party was submitted in June 2018 in the absence of a Minister, to the Permanent Secretary for the Department for Communities.

This letter stated: "In the absence of an Executive and Assembly, we are requesting that a working group is established within the Department for Communities to proactively engage with Scottish officials and other stakeholders to review the current definition and begin the preparatory work required, including an analysis of implications, for the introduction of a definition of terminal illness based on clinical need, rather than any time-restricted understanding of life expectancy.

(A copy of this letter is provided in Annex B).

The current time restricted definition of terminal illness is not accurate. It is not fit for purpose. It excludes many legitimate claimants with an unpredictable disease trajectory. It is cruel and unfair on those in need of welfare support and with the least time to spare. It requires urgent change in line with the approach being taken in Scotland.

Does the six month definition help or hinder people affected by terminal illness to receive the support they need?

People affected by terminal illness who are eligible for social security payments under the Special Rules have a significantly different experience than those who don't qualify for eligibility.

PIP - SRTI claimants do not have to complete the 'How your disability affects you' form; do not need to attend a face-to-face assessment; are entitled to the enhanced rate of the Daily Living component of PIP (£85.60 compared with the standard rate of £57.30 per week) without having to satisfy the normal three month qualifying period; and have their claims processed, on average, more than six times faster than normal claims (2 weeks compared with 13 weeks).

UC - SRTI claimants do not have to take part in Work Capability Assessments and will automatically be treated as having limited capability for work related activity, and therefore will not have to fulfil work requirements to continue receiving their payments.

ESA - SRTI claimants do not have to take part in a work Capability Assessment and will automatically be put in the Support Group without serving the usual 13-week assessment phase. As a result, any award of contributory ESA will also not be subject to the usual 12-month time limit.

The experiential accounts and testimonies of constituents who have accessed welfare entitlement through SRTI, and those who have not qualified for SRTI are stark. For patients affected by a terminal illness with a predictable disease trajectory the current definition appears more helpful. The fast-track process is less stressful and less distressing. However for many people their terminal illness does not have a predictable disease trajectory. They are therefore excluded from the fast-track process and as a result suffer immense anxiety and distress trying to navigate and endure the 'normal' welfare process for the benefit in question.

The current definition of terminal illness was written into the legislation almost 30 years ago, in 1990. In the convening years the nature of dying and prognostication has changed significantly. Advances in medical understanding and treatment means people are now terminally ill for longer and for many terminal illnesses, accurate prognosis can be difficult because of the unpredictable trajectories of these conditions. The rates of progression can vary, and patients may be expected to live for a longer period but die within six months due to a sudden deterioration in their condition. As a result of these factors, the current six month definition in effect excludes many legitimate claimants, particularly those with non-cancerous terminal conditions, from applying for welfare entitlement under the Special Rules for Terminal Illness. They are therefore left to go through the 'normal' process of filling in a weighty application form, may have to go through a face-to-face assessment which can be very distressing and wait up to three months on a decision; three months of worry; three months of very precious time. No one with a terminal illness should have to spend the little time they have left going through this ordeal.

17,000 people in England have died while waiting on a PIP award decision. While it has not been possible to date, to obtain under Freedom of Information Requests the number of people in Northern Ireland who have died while awaiting the outcome of their PIP decision, the SDLP is aware though our constituency and advocacy work of people who have died in these circumstances. This is appalling and another compelling reason for change.

The acid test of a society is how it treats its most vulnerable. The current legal definition of terminal illness is out dated and not fit for purpose. It is also in our view cruel. As long as the six month definition remains on the statute books, we know there will be people either denied access to benefits when they need it or who have to face long delays and invasive assessments. The terminally ill deserve to be treated with fairness, dignity and compassion. It is time for an accurate and fairer definition of terminal illness that is based on clinical judgment, not an arbitrary time restricted estimation of life expectancy. That is the call by affected claimants, their families, carers, charities, experts and academics. That is the judgment of the clinicians in Northern Ireland. It is the recommendation of independent experts commissioned to consult and scrutinize this issue and it is the unanimous conclusion of six political parties in Northern Ireland from across the political spectrum, a rare occurrence in Northern Irish politics particularly in the current divisive context.

The SDLP's strong view and recommendation is that the current definition should be replaced with a definition of terminal illness based on clinical need, rather than any time restricted understanding of life expectancy, in line with the approach being adopted in Scotland. We believe this is not only the right and accurate definition but is also fair and compassionate. We believe this change should be implemented in Northern Ireland and across all regions as soon as possible as the terminally ill in need of support do not have the luxury of time to wait.

<u>Appendix 1</u>

Open letter published in Belfast Telegraph on 7 June 2018

“We are deeply concerned about the impact of the current definition of terminal illness used for eligibility for benefits including Personal Independence Payments (PIP) in Northern Ireland. PIP has special rules for applicants with terminal illnesses, which allows people to access payments quicker and without a face-to-face assessment. However, this avenue is only open to those who have been given a prognosis of six months or less. This restriction is unfairly excluding many people with terminal illnesses.

Over 90 percent of people accessing PIP via the terminal illness rules have cancer, despite the condition accounting for less than a third of deaths in Northern Ireland. This is largely because cancer has a more easily defined disease trajectory and it is easier to predict when someone is in the last six months of life, giving clinicians more confidence to sign off the benefit forms.

Many other terminal illnesses have more unpredictable trajectories and life expectancy is harder to predict accurately. Many terminally ill people, including those with Motor Neurone Disease (MND), chronic heart failure and COPD, fail to access PIP under the special rules, meaning they have to wait much longer for their payments and undergo face-to-face assessments. This is unfair and denies people the best quality of life during the time they have left.

The Scottish Government has adopted a definition of terminal illness based on clinical judgment, rather than a time-bound estimation of life expectancy. We believe the situation should also be reviewed in Northern Ireland with a view to aligning with the Scottish approach. This compassionate model will allow many more people with terminal illnesses to get the help they need when they need it."

Signatories,

Dr Joan Regan (Medical Director, Marie Curie)

Phil Hughes MBE (Director of Community Care, Northern Health and Social Care Trust)

Professor Max Watson (Director of Project ECHO, Hospice UK)

Dr Ian Warwick (Executive Committee Member, Association of Palliative Medicine and Consultant in Palliative Medicine)

Heather Weir (Chief Executive, Northern Ireland Hospice)

Dr Paul McIvor (Medical Director, Foyle Hospice)

Dr Conn Haughey (Consultant in Palliative Medicine, Western Health and Social Care Trust)

Professor Hugh McKenna (Dean of Medical School Development, Ulster University)

Dr Chris Leggett (Chair and GP Lead, Down Integrated Care Partnership)

Heather Monteverde (Head of Services in Northern Ireland, Macmillan Cancer Support)

Dr Bernie Corcoran (Consultant in Palliative Medicine, Belfast Health and Social Care Trust)

Dr Aine Abbott (GP and palliative medicine specialist)

Anne Marie Marley (Respiratory Nurse Consultant, Belfast Health and Social Care Trust)

Dr Gavin McDonnell (Consultant Neurologist, Belfast Health and Social Care Trust)

Fidelma Carter (Public Health Director, Northern Ireland Chest Heart and Stroke)

Cherry Ewing (Macmillan Palliative Care Clinical Nurse Specialist, Western Health and Social Care Trust)

Creea Convery (Regional Care Development Advisor, MND Association Northern Ireland)

Dr Jennifer Doherty (Medical Director, Marie Curie)

Sandra Aitcheson (Nurse Consultant, Public Health Agency)

Sue Patchett (Nurse Education Consultant, HSC Clinical Education Centre)

Dr Carol Stone (Consultant in Palliative Medicine, Marie Curie)

Dr Stephen Todd (Consultant Geriatrician, Western Health and Social Care Trust)

Professor Sonja McIlfatrick (Head of School of Nursing, Ulster University)

Dr Orla Gray (Consultant Neurologist, South Eastern Health and Social Care Trust)

Dr Michael Crawford (GP, Hillsborough Medical Practice)

Miriam McKeown (Hospice Manager, Marie Curie Belfast Hospice)

Tara Collins (Programme Manager, Dementia NI)

Dr Pauline Wilkinson (Consultant in Palliative Medicine, Marie Curie)

Joyce Shaw (Service Manager Neurorehabilitation, Belfast Health and Social Care Trust)

Dr Joan Fyvie (Consultant in Palliative Medicine, Marie Curie)

Emma King (Macmillan Specialist Palliative Care Team Manager, Western Health and Social Care Trust)

Dr Gillian Mullan (Consultant Lead Clinical Psychologist for Older People, Western Health and Social Care Trust)

Dr Felicity Hasson (Senior Lecturer, Institute of Nursing Research, Ulster University)

Deirdre McKenna (Senior Social Work Practitioner in Palliative Care, Southern Health and Social Care Trust)

Dr Gareth Hiscocks (GP, Donagheadee Health Centre)

Dr Simon Goldring (GP, Brook Street Surgery)

Dr Karen Harkin (GP, Draperstown Surgery)

Ria Malone (MND Specialist Nurse, Belfast Health and Social Care Trust)

Dr Sheila Kelly (Consultant in Palliative Medicine (retired))

Lynn O'Hara (Community Heart Failure Nurse, Belfast Health and Social Care Trust)

Dr Amy Doherty (GP, Eglinton Medical Practice)

Dr Neil McKeon (GP Partner, Aberfoyle Surgery)

Dr Sara Graham (GP, Brook Street Surgery)

Lesley McCorry (Community Specialist Multi-disciplinary Palliative Care Team, Southern Health and Social Care Trust)

Marie Morrissey (Day Hospice and Outpatient Services Manager, Marie Curie)

Fiona Patterson (Community Specialist Multidisciplinary Palliative Care Team, Southern Health and Social Care Trust)

Dr Joanna McCreery (GP, Brook Street Surgery)

Dr Katharine Crowe (GP, Donaghadee Health Centre)

Gillian Thomas (Macmillan Specialist Palliative Care Social Worker, Western Health and Social Care Trust)

Noreen Watts (Community Palliative Care Sister, Belfast Health and Social Care Trust)

Dr Graeme Crawford (GP, Bangor Health Centre) Dr Joanne Davis (GP, Donaghadee Health Centre)

Dr Ann Donnelly (Speciality Doctor in Palliative Medicine)

Colette McCullagh (Occupational Therapist, Specialist Palliative Care Team, Western Health and Social Care Trust)

Dr Alyson McVeigh (GP, Donaghadee Health Centre)

Ann McSorley (Macmillan Specialist Palliative Care Team, Western Health and Social Care Trust)

Dr Jenny Gingles (Consultant in Public Health (retired))

Lydia Scholes (Senior Social Worker, Southern Health and Social Care Trust)

Suzi Hughes (Social Worker, Southern Health and Social Care Trust)

Laura Millar (Social Worker, Southern Health and Social Care Trust)

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All Party Parliamentary Group
for Terminal Illness

Appendix 2

17 June 2018

Mr Leo O'Reilly

Permanent Secretary for the Department for Communities

By Email

Dear Mr O'Reilly

We are writing to you in relation to the current definition of Terminal Illness applied in Northern Ireland in the PIP process. You will be aware of developments in Scotland and the new amendment to the Welfare Bill which states:

(2) The regulations must provide that an individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if, having had regard to the guidance mentioned in sub-paragraph

(3), 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.

(3) The Chief Medical Officer of the Scottish Administration is—

(a) following consultation with registered medical practitioners, to prepare and from time to time revise, and

(b) to make publicly available by such means as the Chief Medical Officer considers appropriate, guidance that sets out when a progressive disease can reasonably be expected to cause an individual's death for the purpose of determining entitlement to disability assistance.

Clinicians across Scotland, with terminally ill charities and advocates, led calls for this move towards a definition of terminal illness based on clinical need, rather than any time-restricted understanding of life expectancy. You will be aware of the recent publication of the open letter signed by 60 clinicians and health experts across Northern Ireland calling for the same move so the same dignity and fairness can be afforded to terminally ill people here. The same call has also been made by Marie Curie NI, Dementia NI, Alzheimer's Society, MNDNI and other Northern Ireland charities representing the terminally ill.

In the absence of an Executive and Assembly, we are requesting that a working group is established within the Department for Communities to proactively engage with Scottish officials and other stakeholders to review the current definition and begin the preparatory work required, including an analysis of implications, for the introduction of a definition of terminal illness based on clinical need, rather than any time-restricted understanding of life expectancy.

Yours sincerely,

Nichola Mallon MLA SDLP

Keith Buchanan MLA DUP

Alex Maskey MLA SF

Andy Allen MLA UUP

Naomi Long MLA Alliance

Steven Agnew MLA Green Party