

## Written evidence from Macmillian Cancer Support [SWP0055]

### Executive Summary

1. Evidence emerging from Macmillian's Welfare Rights services indicates that the welfare system is not coping with current demand, and we have serious concerns about the ability of people with cancer to access support during the COVID-19 outbreak.
2. People with cancer are experiencing long waits on the telephone lines to claim UC and New-Style ESA. We are calling on the Government to commit more resource to ensure people can complete claims and get issues resolved quickly.
3. Many of the measures introduced by the Government are welcome and should be extended following the COVID-19 outbreak, including relaxing requirements to attend a Jobcentre as part of UC applications, and reducing the number of face-to-face assessments.
4. However, we believe the Government should provide clearer information and guidance on the measures introduced, including an immediate clarification for employers that they should furlough people who cannot undertake available work due to shielding. The Government must also take action to ensure employers are treating shielding employees equally with other employees who are not at such high risk.
5. It is disappointing that the Department has not taken steps to remove the 5-week wait for UC. Many people with cancer face a financial shock at the point of diagnosis and waiting 5 weeks for their first UC payment puts them at risk of additional stress, anxiety and hardship.
6. The Department could facilitate advice services to support people better by relaxing consent requirements, to enable advisers to initiate claims on behalf of clients.
7. Advice services are also impacted by delays on telephone support lines, as this is the only route available to follow up issues experienced by clients. The Department needs to provide additional resource to ensure that organisations can engage with it effectively on behalf of people who need support.

### Introduction

8. Macmillian Cancer Support is a registered charity providing information and support to people with cancer, including specialist support to people with cancer accessing the welfare system.
9. In 2018, Macmillian's face-to-face benefits advisers reached 140,982 people affected by cancer, and our telephone Support Line welfare rights team supported 25,152 people with cancer.
10. Since the outbreak of COVID-19, calls to Macmillian's Support Line service have increased as people with cancer seek support with the impact of the outbreak. Currently, around 1 in 3 (1,155) calls to our Support Line are related to COVID-19.

### How well is the Universal Credit system working for the unprecedented numbers of new claimants?

11. We understand that the Department is facing unprecedented levels of demand, as hundreds of thousands of people impacted by the COVID-19 outbreak seek to access support from the welfare system. We appreciate the efforts the Department is making to manage this, including redeploying staff to process Universal Credit (UC) claims.

12. However, evidence emerging from our services indicates that the system is not coping with demand, and we have serious concerns about the ability of people with cancer to access support at this time.
13. Even prior to the outbreak we heard from our advice services that the telephony and online systems within UC do not interact well with each other, and many people face long waits across the Department's telephony service – including the UC helpline.
14. Evidence from Macmillan's Support Line Service over the last two weeks has indicated that these problems have got worse, with people waiting many hours on hold when calling telephone help lines, and cases of people being cut off before they got through to a DWP staff member.
15. This not only impacts people who are trying to make telephone claims, but those who experience an issue with an online claim and need to call the helpline for support. If they are not able to get through these issues remain unresolved and delay the registration of a claim.
16. We have heard of examples of people getting through to DWP staff but being told that there are problems with the system, or that their records cannot be accessed and to try again later.

**What lessons can be learned from the changes that have been made to the processes for verifying the identity of UC claimants? Are there any particular changes that should stay in place after the outbreak ends?**

17. We welcome the measures taken by the Government to remove requirements for claimants to attend Jobcentre Plus as part of their UC claim. This recognises that attending appointments at busy, open environments such as a Jobcentre puts people at risk of infection with COVID-19.
18. Many people with cancer are at particularly high risk from COVID-19, including people having certain cancer treatments, and people with blood or bone marrow cancers. These people are not just at risk during the COVID-19 outbreak, but have reduced immunity to all infections, often for extended periods.
19. Macmillan has been calling on the Government to relax requirements for attending Jobcentre appointments within the UC application for some time. Many people with cancer, especially those having chemotherapy, are at increased risk of infections and will be advised to avoid public spaces in normal circumstances, not just in the context of COVID-19.
20. Whilst there are alternatives available for some appointments e.g. online identity verification or the home visiting service, these are often not well publicised or accessible, and our services report that many people with cancer are required to attend a Jobcentre at least once to complete their claim. This puts people at risk of infection and can be against medical advice, which can add to stress at an already difficult time.
21. We would recommend that after the outbreak ends the Department retains flexibility around attending Jobcentres, including enabling ID verification to be completed over the telephone.
22. The wider flexibility the Department has shown across disability benefits has been welcome, including the suspension of face-to-face assessments. After the COVID-19 outbreak ends we would recommend that the Department explores where face-to-face assessments can be avoided, e.g. by giving greater consideration to different types of available evidence.

**How effective have DWP's communications with the public been during this period?**

23. The Department have put considerable effort into keeping organisations informed of the latest policy and process changes introduced to respond to the COVID-19 outbreak.
24. However, emerging evidence from our advice services indicates that there is some confusion about who the different measures apply to. This appears to be a particular issue for people who do not have COVID-19 symptoms, but are shielding, self-isolating as a precaution, or live in a household with someone who is shielding or self-isolating.
25. Macmillan's advice services play a vital role in supporting people with cancer to understand their entitlements and navigate the system. The pace at which changes have been delivered is welcome but has left some gaps in terms of the guidance provided for people in specific circumstances.
26. These include a lack of clarity around how people who are self-isolating because of a cancer diagnosis, rather than COVID-19 symptoms, get access to Government support schemes, and if they are entitled to Statutory Sick Pay (SSP) from Day 1 or Employment Support Allowance (ESA) without the need for 7 waiting days.
27. There is also some confusion about what support those who will seek to access the Government Self-Employed Income Support Scheme in June should claim in the meantime, and what impact accessing UC or New-Style ESA will have on their entitlement to the scheme.

**How easy is it for people to understand what they're entitled to claim? For example: Is it clear enough how the benefits system interacts with other forms of Government support during this period, such as the Coronavirus Job Retention Scheme? Is it clear enough how public health guidance interacts with the benefits system?**

28. People most at risk of COVID-19 are being encouraged by the Government and the NHS to take extra steps to prevent infection, known as 'shielding'. This group includes people having certain cancer treatments, and people with blood or bone marrow cancers. Many other people with cancer may not be in the Government defined 'vulnerable' group but could be advised by their clinician or choose to 'shield' as a precaution.
29. According to Government guidance, people who are unable to work due to shielding can be placed on furlough by their employer. However, emerging evidence from our advice services suggests some employers are not furloughing employees who are shielding due to cancer, and instead encouraging them to 'go off sick' and receive SSP. There have also been some reports of employers furloughing healthy employees but refusing to offer this to people who are vulnerable or shielding.
30. We are concerned that people with cancer may be being excluded from furlough protections, which puts them at a significant financial disadvantage, with the only support they are entitled to being SSP – which some people may have exhausted during extended periods of sick leave prior to the COVID-19 outbreak – ESA or UC if they are eligible.
31. We would urge the Government to provide immediate clarification for employers that they should furlough people if they cannot undertake available work due to shielding. The Government must also take action to ensure employers are treating shielding employees equally with other employees who are not at such high risk.
32. When shielded people do need to apply for ESA or UC, it is unclear what evidence they will need to provide to the DWP. Pressure on clinical capacity during the COVID-19 outbreak is expected to mean that accessing medical evidence such as fit notes is more difficult and takes longer than usual.

33. We recommend that people who are shielding are able to use the letter received from the NHS informing them of their high-risk status as evidence of Limited Capability for Work when applying for ESA or UC.
34. For those who are shielding because they are undergoing or recovering from cancer treatment, this letter should also be accepted as evidence of Limited Capability for Work-related Activity.

**How is the assessment process for Employment Support Allowance working? Have there been any difficulties with obtaining medical evidence to support claims?**

**Employment and Support Allowance applications**

35. The pressure on the UC telephony system caused by unprecedented demand for the benefit does not just impact those seeking to apply for UC. Since the COVID-19 outbreak the main route to make a new claim for contributory or New-Style Employment Support Allowance is through the UC helpline.
36. This is concerning because it exacerbates the delays, and because our advice services have reported for some time that people who try to make a claim for New-Style ESA through the UC telephone line are often given incorrect advice by DWP staff, and advised to claim UC.
37. Our advice services report receiving conflicting information about whether there is an alternative application process for New-Style ESA. We have received calls from people who have called the UC helpline to claim New-Style ESA and have been directed online. However, it is only possible to download a form online, there is no route to submit the form by post or email.
38. The Department should immediately clarify the process people should be following, and explore introducing an online or paper-based system for New-Style ESA applications, to free up capacity on the UC telephone line during the COVID-19 outbreak and ensure people can get access to their entitlement as quickly as possible. This should be extended beyond the outbreak so that people with cancer are not required to attend a Jobcentre to submit their form.

**Assessments**

39. Following the welcome suspension of face-to-face assessments, we are awaiting clarification from the Department around how paper-based and telephone assessments are expected to work.

Medical evidence

40. For people who are awaiting, undergoing or recovering from cancer treatment, a signed UC50 or ESA50 form completed by their clinician outlining the details of their cancer treatment plan and expected side effects allows them to be automatically placed in the LCWRA/Support Group. We are concerned that pressure on clinical teams, and social distancing or shielding restrictions will make accessing these signed forms difficult for many people with cancer.
41. Many people rely on providing additional medical evidence to support their face-to-face assessment, particularly as the staff carrying out these assessments often do not have specialist knowledge of the complexities of cancer and the range of ways it can impact someone.
42. Pressure on medical professionals, and advice services, as a result of COVID-19 mean that the support many people with cancer rely on will be difficult or impossible to access.

We would therefore encourage the Department to make decisions much more flexibly during this period.

#### How the assessment will work

43. When people with cancer do undergo face-to-face assessments, across both PIP and ESA, we know that the questions asked are narrow and closed, which can prevent people giving a full account of their condition and how it impacts their ability to work or their daily life.
44. Many people with cancer also report a lack of clarity around what information is being taken into account during an assessment and rely on support from advice services to gather and provide evidence that will be relevant.
45. We would therefore be concerned if the Department was using the same criteria, questions during telephone assessments, and evidence requirements to make decisions during the COVID-19 outbreak.
46. Decisions about entitlement should be made based on existing evidence that a claimant is able to provide. Reports from our services indicate some cases where the Department appear to have contacted a support service used by a claimant to gather information about their condition.
47. The Department should not require people to gather additional evidence or independently attempt to gather evidence without the claimant's knowledge and permission, as this may be irrelevant and lead to inaccurate decision-making.
48. If the Department cannot make robust decisions on this basis, they should consider postponing assessments altogether and introducing interim awards to ensure that people get the support they need quickly.
49. We are also awaiting urgent clarification from the Government on the position of people who had face-to-face assessments booked in the coming weeks. Our services have reported calls from people who have had appointments cancelled but have been given no further information about how or when a decision will be made.

#### **Have people who were already claiming benefits when the outbreak began seen any changes to the support they receive from DWP?**

50. As outlined above, delays are widespread on the UC telephone line, which does not only impact new claimants. People who are already receiving UC but have issues or queries about their claim are also struggling to get through to the Department to get these resolved.
51. We also have concerns that the pressure on the DWP's capacity to process UC claims is having a knock-on impact on other areas of the system. With staff redeployed to process UC claims, there are gaps emerging in other areas of the system, which are preventing people with cancer getting access to their entitlements. Some initial examples of this emerging from our services include:
52. A caller who was receiving ESA and had requested the addition of the Severe Disability Premium (SDP) a few weeks ago and has now been told it's not currently a priority for processing. This will have a long-term impact on the support available to the individual, both from the monetary value of the SDP and the gateway it provides to other entitlements.
53. A caller who was receiving UC and has recently started chemotherapy so should have the LCWRA element added but has not yet received a UC50 form.
54. To support transparency and the allocation of additional resource during this period, the Department should publish data outlining how the system is coping with demand. This

should include statistics on UC claims processed and payment timeliness, but also some broader indicators across other benefits and processes to identify where demand for resource to process UC claims is leaving gaps elsewhere in the system.

**Are people who are claiming benefits receiving enough money to cover their basic living costs during this period?**

55. The welfare system plays a vital role in the lives of people who are financially impacted by a cancer diagnosis. People with cancer can face a significant financial impact, often from a combination of having to cut down or give up work, and additional costs from travelling to treatment or higher bills.
56. Social security can and should provide people with enough money to maintain a reasonable and dignified lifestyle. It should also play a positive role in people's lives by enabling them to cover the costs of things that promote their wellbeing and quality of life, ensuring they continue to feel like themselves and maintain good mental health whilst they are coping with cancer.
57. Our research with people with cancer indicates that often the support they receive from the welfare system does not deliver this. In the context of COVID-19, it is possible that for many people with cancer their costs will rise, given the likelihood that support from family or friends and voluntary sector services may not be available.
58. It is welcome that the Government has uprated the UC standard allowance, but we continue to have concerns about the financial support available during this period.
59. It is disappointing that the Department has not taken steps to remove the 5-week wait for UC. Many people with cancer face a financial shock at the point of diagnosis and waiting 5 weeks for their first UC payment puts them at risk of additional stress, anxiety and hardship. In the context of COVID-19, the need for quick access to financial support is more urgent than ever.
60. The Department has argued that removing the 5-week wait entirely is not operationally feasible in the current climate. Whilst appreciating the challenges the Department faces, it has proved that flexibility can be built into the system, for example through suspending deductions for benefit overpayments, so it is disappointing that similar measures have not been explored to at least mitigate the impact of the 5-week wait further.
61. We are also very concerned that recent communications from the Department to stakeholders have indicated that advance payments will not be reviewed, as the financial impact of repaying an advance is expected to be absorbed by the increase of the UC standard allowance.
62. The uprating of UC was welcome recognition that the welfare system is often not providing enough support for people to manage. Allowing uprated levels to be eroded by deductions for advance repayments is unacceptable, and undermines the welcome extra support provided by the Government.
63. While UC has been uprated, similar measures have not been taken to increase legacy benefits. This is likely to leave some people with cancer, such as those receiving ESA (without entitlement to the Severe Disability Premium), worse off than those who have already moved to UC.
64. This could have the effect of triggering these people to move to UC earlier than they would have done otherwise, which would in some cases leave them worse off in the longer-term, for example if they were later found eligible for PIP and by proxy the SDP.
65. More broadly, the COVID-19 crisis is likely to trigger people to migrate to UC from legacy benefits earlier than they might have done otherwise. For example, people with cancer

who were previously only receiving ESA may now need to seek support with housing costs, which would trigger a natural migration to UC.

66. People who naturally migrate to UC as a result of COVID-19 will not be entitled to and Transitional Protection, which would have prevented losses of income during the Government initiated managed migration process.
67. The Government should uprate legacy benefits, including ESA, in line with the increase to the UC standard allowance, to prevent those receiving legacy benefits losing out financially in the short-term, or migrating to UC earlier than they otherwise would have, which could have long-term financial implications.

**Are support organisations and charities able to access the resources they need from DWP to support vulnerable people? What more could DWP be doing to facilitate that support?**

68. Engagement teams within the DWP have put significant effort into keeping organisations and charities up to date with policy and process changes and answering queries that are shared with them.
69. However, there are still some areas where guidance is not clear or detailed enough, and our advice services are not able to find the answers to individual callers' queries in published advice.
70. It would be helpful for the DWP to provide more detailed guidance for advice services, and for this to be publicly available to support people to understand their entitlements and the processes they need to follow.
71. Many organisations are having to adapt the services they deliver in the context of COVID-19, e.g. benefits advisers switching to remote working. This creates challenges when supporting very vulnerable clients, particularly those without internet access or who struggle with using the telephone or completing forms.
72. The Department could facilitate advice services to support these people better by relaxing consent requirements, to enable advisers to initiate claims on behalf of clients.
73. Advice services are also impacted by delays on telephone support lines, as this is the only route available to follow up issues experienced by clients. The Department needs to provide additional resource to ensure that organisations can engage with it effectively on behalf of people who need support.

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