

Dame Cally Palmer DBE
National Cancer Director
NHS England
PO Box 16738
Redditch
B97 9PT

5 June 2020

Dear Dame Cally

The Blood Cancer Alliance is a group of 14 charities representing patients with blood cancers across the UK. We are writing to raise a number of issues that have arisen for our patients during the COVID-19 pandemic.

We welcome the step by NHS England to establish an advisory group tasked with finding recommendations to improve physical and mental health provision for those patients shielding during the pandemic, and given the issues outlined below, ask that blood cancer patients be represented on this group.

The process of identifying blood cancer patients as 'extremely vulnerable' and notifying them of their status has been too slow. Across our membership, requests for support on this subject have dominated calls to our patient helplines throughout lockdown. We are aware that some blood cancer patients still have not received letters confirming their status or offering any shielding advice, and this is a particular problem in rarer haematological malignancies such as MDS. These patients are often unable to access further support such as assistance with shopping and procuring medical supplies, without this confirmed status, and therefore forced to put themselves at risk by breaking with shielding advice. While we understand they can self-identify, we have also been made aware that there has been significant delay in confirmation of their status regardless of this action.

More worryingly, we are now beginning to receive requests for support from patients who have been asked to return to work as lockdown measures ease. These patients do not have any paperwork to present to employers identifying them as vulnerable and needing to shield. Absent to this, employers are pressuring these patients to return to workplaces, which Government ministers themselves have acknowledged will be challenging to keep safe.

The confusion and stress our patients feel has been exacerbated by changes to shielding advice in the past week. This was done with limited notification of, or consultation with, patient representative groups. Equally, no evidence has been presented as to why the risk level has changed for blood cancer patients and other vulnerable groups. There also appears to be conflict between Government advice and the advice patients are receiving from their NHS care provider.

We would welcome any support you can give in ensuring the process of notifying all blood cancer patients of their status – including those with rare blood cancers and haematological malignancies - is completed with the upmost urgency now. It should also be noted that newly diagnosed patients will need to be identified and receive all appropriate advice and support. This must be combined with clear and evidence-based advice on shielding measures and any relaxation of them. It would help our support workers immeasurably if we can be notified of changes in shielding advice in advance, and be made privy to supporting evidence.

While many blood cancer patients may be more acquainted with self-isolation than the general population, there is still a need for urgent consideration of what can be done to provide both physical and psychological support during the shielding period. While lockdown measures are easing

for the majority of the population, there is no end in sight to shielding isolation for blood cancer patients.

Living with blood cancer can take a huge psychological toll in normal times. Patients are now living with their condition with very limited access to support and care from loved ones, no ability to undertake any of their usual daily activity that would provide relief, and confusing advice from Government. This anxiety and stress is also likely to be being exacerbated by treatment delay, pressure to return to work, lack of practical support - or potentially a combination of all three. We would also like to highlight the additional anxiety felt by our BAME blood cancer patients, given the higher risk COVID-19 appears to pose to that community, and the potential need for additional support for that group.

Lastly, we would like to raise that many blood cancer patients are experiencing treatment delay, as the risk posed by COVID-19 in hospitals is deemed too high. The creation of clean sites for cancer patient treatment, including drug-based, chemo- and radiotherapies, must be established as rapidly as possible, given the link between delayed treatment and poorer outcomes. Moreover, many recovering from successful blood cancer treatment will still be severely immune-compromised, and therefore unable to access follow-up care services while shielding. More must be done to offer care in safe settings and in the home where possible.

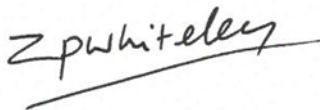
We would therefore strongly welcome greater consideration within the NHS and Government as to what more can be done to provide better psychological support and safe physical care services for blood cancer patients during this challenging time.

In summary, it is clear to us what is now needed to dramatically improve the experience of blood cancer patients during the pandemic:

- All blood cancer patients must receive notification of their status and given clear and consistent shielding advice which is driven by input from leading clinical expert groups.
- Greater consideration of what psychological support can be offered to those patients shielding with no end in sight, including specific consideration of BAME patients.
- Rapid establishment of safe facilities for blood cancer treatment and post-treatment care

I would welcome an opportunity to discuss these matters with you or contribute formally to the new advisory group.

Yours sincerely,



Zack Pemberton-Whitely
Chair
Blood Cancer Alliance

Cc Professor Peter Johnson CBE, Dr Raj Patel MBE