

CANCER LEADERSHIP COUNCIL

A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS
ADDRESSING PUBLIC POLICY ISSUES IN CANCER

January 31, 2020

Andrew Saul
Commissioner
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235

RE: SA-2018---26, Rules Regarding the Frequency and Notice of Continuing Disability Reviews

Dear Commissioner Saul:

The undersigned organizations represent cancer patients with all forms of cancer in their pursuit of quality cancer care and high quality of life throughout their cancer journey. Some of the cancer survivors we represent become disabled because of their cancer and cancer treatment. These patients must, of course, undergo the disability determination process and also submit to continuing disability reviews at the intervals currently designated for their condition.

Both the initial eligibility process and the continuing disability review (CDR) process are very burdensome on people with cancer and their families. Because the proposed rule would make significant changes in the CDR process for those with cancer, we will focus especially on how people with cancer manage that process. Both the full medical form for CDRs and the mailer form require beneficiaries to dedicate significant time, effort, and expense to complete. In the case of children with cancer, the burden falls on parents who are struggling to care for their children and manage their children's disease and treatment for it.

We have reservations about the proposals to establish a fourth medical diary category and to alter the assignment of conditions to each diary category in large part because they fail to assess the impact of CDR changes on disability beneficiaries. We also believe that the Social Security Administration (SSA) has failed to provide a clear rationale for establishing a new medical diary category of "medical improvement likely" and also failed to articulate the standards for assignment of conditions to the diary categories.

The SSA has authority to recommend standards for CDRs at intervals more frequent than anticipated in the statute, but it must offer reasons to support more frequent CDRs. In the proposal, SSA has not met this requirement. By failing to consider the impact of its proposal on beneficiaries or provide a rationale for the new diary category and assignment of conditions to categories, SSA has fallen short of its notice-and-comment rulemaking responsibilities. The public is not provided adequate information about the proposed rule and the evidence behind the rule to permit them to offer comments.

The New Diary Category, Medical Improvement Likely

SSA proposes to establish a new diary category of medical improvement likely, with requirement of CDR every two years. This would represent a more rapid cycle for CDRs than required under the “medical improvement possible” diary category, which requires CDRs every three years. SSA has not identified the data that would support the establishment of a fourth diary category.

In the proposed rule, the agency identifies “advances in medical technology and treatment that has improved outcomes for many impairments.” These advances seem to be the evidence on which the agency relies for assignment of conditions to diary categories. Although the agency does not directly state this, we infer that the advances in medical treatment referenced by SSA may also represent the evidence to support the establishment of the new category with a two-year CDR time-line.

The agency has provided no rigorous analysis to support the new diary category, and we question the general reliance on recent medical treatments to establish the new diary category or assign conditions to categories. We are aware of a number of new technologies and treatments for cancer developed and utilized by patients in recent years. However, if the agency intends to rely on these advances to support any CDR changes, it must analyze the impact of these treatment advances in the real world. In the case of cancer treatment advances, their impact must be analyzed in clinical practice and not just according to outcomes listed in product labeling. The impact on outcomes that is observed in clinical trials may be enjoyed by some but not all patients. In addition, any analysis of new treatments should include information about the burden associated with a new treatment, including the issues associated with compliance with the treatment and the management of treatment side effects. In addition, and this is a very important consideration for determining disability and for continuing disability reviews, the late and long-term effects of any new treatment must be considered. In the case of cancer therapies, the long-term effects of treatment may themselves be disabling conditions.

The Assignment of Conditions to Diary Categories

The proposed rule does not include a standardized process for the assignment of conditions to the medical diary categories. The proposed rule references a supplementary document that addresses “Impairment Placements in CDR Categories.” Table 2 of this supplementary document lists a number of cancer diagnoses – in adults only, adults and children, and children only – as impairments that will be included in the medical improvement likely (MIL) category. These diagnoses include cancer of the testes, multiple myeloma with bone marrow or stem cell transplantation, lymphoma, leukemia, retinoblastoma, neuroblastoma, and malignant solid tumors, among others.

We are concerned that there has been no meaningful analysis – and no standardized process – for assigning these impairments to the MIL category. As we discuss above, the development of new treatments for these impairments – these cancers – does not necessarily mean that there will be immediate medical improvement for these conditions. There is no meaningful discussion in the supplementary document of the standards for assigning these conditions to MIL category.

We understand that the agency will not change the review standards for CDRs, and this is a decision that we support. However, this decision to retain current review standards provides limited assurance about the impact of the proposed changes in CDRs – new diary categories and assignment of conditions to categories -- on cancer survivors. The changes will subject many cancer survivors to CDRs on a more accelerated schedule, which means subjecting them unnecessarily to reviews that are burdensome and upsetting even if the final result is no discontinuation of disability benefits.

Potential Impact of CDR Changes on Access to Health Care

In its discussion of the proposed changes in continuing disability review diary categories and assignment of conditions to categories, SSA references medical technology and treatment advances. The agency also says that it has considered disabled beneficiaries’ access to health care in assessing medical improvement and when and how it should be assessed. The agency writes, “For many disabling impairments, the key element for MI is a person’s receipt of treatment that can decrease the severity of the impairment and its effects.” The agency goes on to explain the MIL category by stating, “The MIL diary category will allow us to assess MI after some beneficiaries benefit from access to health care through Medicare or Medicaid to determine if they continue to be eligible for benefits.”

Although we are somewhat gratified to see that the agency understands that access to care is critical to medical improvement, we note the failure of the agency to acknowledge that disabled individuals gain access to Medicare and Medicaid through their disabled status (and in the case of Medicare, after a two-year delay for most). They will lose that access to care if they lose their access to disability benefits.

This loss of access to care through Medicare or Medicaid may be crippling for those who are living with chronic diseases, including many forms of cancer. We return to the decision of SSA to propose a new diary category and new standards for assignment of conditions to categories. As we have argued above, the agency has undertaken inadequate analysis to support either action. But we infer from some statements in the proposed rule that the agency has looked at new medical technology and treatments and classified them as cures for certain conditions, including many cancers. And the agency has based its new diary category and assignment of conditions on these conclusions. That assumption is in many cases inaccurate, as important new technologies may lengthen and improve lives but may also be chronic treatments required over the course of a disabled person's lifetime. Losing access to care and to those new treatments will eliminate the medical improvement that SSA hopes to detect at the earliest possible time. Many forms of cancer – including some of those included in the MIL category – are chronic diseases that require a lifetime of treatment. The assumption of SSA that access to care through Medicare and Medicaid will result in medical improvement may be accurate. However, this medical improvement may be fleeting if beneficiaries lose their disability benefits and also access to Medicare or Medicaid.

Impact of Loss of Disability Status on Earnings, including Family Income

SSA has provided no convincing evidence that more frequent CDRs will increase workforce participation. We direct special attention to the assertion that “parents of SSI children who medically improve offset the loss of SSI benefits through earned income.” The agency must provide more data to support this assertion, which is not a trend that we observe among families with a child with cancer. In addition, as we have explained above, the loss of SSI benefits may mean the loss of Medicaid benefits. We see no analysis from the agency about the potential impact of this loss of access and the resulting financial and medical benefit on children with cancer and their families. A complete analysis of how families will fare after removal from disability rolls must include consideration of how families will pay for health insurance.

CDR Backlogs

In the last two decades, SSA has struggled to manage its CDR workload. SSA eliminated a longstanding CDR backlog in CY 2002, but in subsequent years CDR backlogs have occurred again and been eliminated again. As of the fall of 2019, there was a substantial backlog of CDRs at state agencies. We are concerned that the agency has not evaluated how the medical improvement likely category with a two-year interval for CDRs will affect its backlog and the beneficiaries who will be subject to the new CDR interval when a backlog already exists.

We urge SSA to reconsider the new medical category and the assignment of many cancer patients to this category. We believe that these proposals will trigger unnecessary reviews that will not meet a fundamental goal of SSA to identify medical improvement at the earliest possible time. Instead, we are concerned that SSA could be establishing a system that finds beneficiaries in the middle of one CDR that is still not complete when they receive notice of a second CDR. This is not an acceptable solution for beneficiaries, their families, the SSA, or the taxpayer. But it is one that is possible – if not likely – under the proposed rule.

Conclusion

We urge SSA to withdraw the proposed rule and to begin a new effort to refine the CDR process that relies on solid data that might support changes in diary categories or assignment of conditions to categories.

SSA notes in the proposed rule that when Congress passed the Social Security Disability Benefits Reform Act of 1984, Congress offered a caution that “people who are found eligible for benefits after a lengthy administrative appeal not find themselves subjected to a second eligibility review after only a relatively brief period.” We are concerned that this will be exactly the result of the proposed rule. Cancer patients whose conditions are in the new medical improvement likely diary may find themselves in a cycle of CDR after CDR, all imposing considerable burden on them even if their benefits are not terminated.

Sincerely,

Cancer Leadership Council

Academy of Oncology Nurse & Patient Navigators

CancerCare

Cancer Support Community

Children’s Cancer Cause

Fight Colorectal Cancer

International Myeloma Foundation

Leukemia & Lymphoma Society

Lymphoma Research Foundation

National Coalition for Cancer Survivorship