## STATE OF SURVIVORSHIP

 SURVEY: 2021
## SUPPORT SYSTEMS ARE KEY

## \$NCCS

NATIONAL COALITION
FOR CANCER SURVIVORSHIP

## SUPPORT SYSTEMS ARE KEY

Patients' consistent top piece of advice they give to others is to make sure to have a support system after receiving a cancer diagnosis. Rebecca was in her late 40's when she was diagnosed with a Stage II breast cancer. She did, and still does, struggle with many common side effects like lack of energy, bone pain, nausea, hair loss, anxiety, depression, brain fog, and brittle bones.

Despite these side effects, Rebecca says her five years of treatment and care have been excellent. She credits her strong support system that includes family, friends, her community, programmatic financial support, and a quality health care team led by her oncologist.

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"Have a support system."
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\#1 Piece of advice given by patients to others after receiving a cancer diagnosis.

The sources of support Rebecca found mirror our survey data. Immediate family is a source of support for $84 \%$ of respondents. Doctors and health care teams were support for $71 \%$, and friends were a source of support for $65 \%$ of patients. Other areas of support included faith (41\%), extended family (41\%), and work colleagues (20\%). Other sources, including churches, advocacy organizations, support groups, and social media were reported by $20 \%$ or less of patients.

Sources of Support
PROVIDED SUPPORT PROVIDED MOST SUPPORT


I had a team of friends. One took care of meals, connecting with other families. One was like my advisor, the person I thought everything through with. People just showed up and rolled up their sleeves and didn't even let me ask. When I look back, I just know how much love there is out there. It's hard to accept help when you are independent like I am, but I really had no choice.

About half of the national sample describe the support they received as excellent. However, the data continue to show large disparities along the lines of age, gender, income, how informed patients felt, and how they rated the quality of their care. Notably, perceptions of the quality of care align closely with levels of support. Among patients who rate the quality of their cancer care as excellent, $64 \%$ also indicated they had excellent support. On the other hand, among patients who rated their cancer care as fair or poor, only $4 \%$ felt they received excellent support.

Similarly, of those who felt very informed about side effects, $62 \%$ said they received excellent support, while only $22 \%$ of patients rated their support as excellent when they felt they were not well-informed about side effects.

## Respondents Who Rated Support as Excellent



HOW INFORMED FEEL ABOUT SIDE EFFECTS


Immediate family ranks highest in providing the most support among patients, $58 \%$ say it was their biggest source of support. Younger, Hispanic/Latino, Black, and low-income patients were less likely to depend on immediate family. And while Black and low-income respondents tended to lean on their faith more than other respondents, a larger percentage of Hispanic/Latino patients said they rely on their doctor/health care team for the most support compared to other patient groups.

## Biggest Support Systems



Rebecca received strong support from her oncologist, whom she says was clearly steering the ship of her care and treatment. She cited numerous examples of compassionate and professional members of her health care team from radiologists, nutritionists, physical and mental therapists, along with aid workers who helped set her up on Medicaid to handle the medical costs.

She had communities of friends who worked to set up meals, clean her house, drive her to appointments, and set up fundraisers. One friend even flew across the country on a moment's notice to provide emotional support. Her health care team told her they had never seen a patient with so much community support.

Rebecca's experience illustrates what the survey data show: when support systems are solid-a quality health care team, vested family and friends, programmatic financial support-patients have a higher chance at better experiences and outcomes.


As NCCS continues to advocate for equitable access to quality care and financial support, the data also show that we in the patient advocacy community need to reach more people. In the national sample, less than $10 \%$ said they found support from patient advocacy organizations, groups on social media, and patient support groups. Yet for NCCS-connected respondents, $24-33 \%$ said they found support in those spaces. While families and health care teams are, and should be, the best systems of support for most, patient advocacy organizations can provide additional systems of support by engaging more patients.

## Connected Patients Access Support from Additional Sources



# sNCCS 

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