MDForLives

THE GLOBAL PULSE OF HEALTHCARE · CANCER PATIENT INSIGHT REPORT

Cancer and Mental Health: Why Emotional Support Can Be Hard to Reach

A patient-centered view of anxiety, emotional distress, support gaps, referral barriers, and what could make mental health support easier to reach during and after cancer care.

DIAGNOSIS → TREATMENT → EMOTIONAL DISTRESS → SUPPORT → FOLLOW-UP

94	6	68.1%	9017382
Survey records	Countries represented USA · UK · Canada · Italy · France · Germany	Completion rate	SGID

WHY THIS REPORT

Cancer care can be clinically organized while the emotional experience still feels difficult to navigate.

A diagnosis can change how someone thinks about their health, future, family, work, body, and sense of control. Treatment may add fatigue, pain, uncertainty, appointments, waiting, and financial or practical strain. Emotional support can help, but patients still need a clear way to recognize distress, talk about it, and reach the right level of support at the right time.

This report examines where emotional distress appears in the patient journey, who identifies it first, what support is offered, what gets in the way, and what patients think could improve the system. The purpose is not to suggest that every patient needs the same mental health intervention. It is to understand how support pathways work, or fail to work, from the patient side.

CLINICAL CONTEXT

Distress is part of cancer care, and it can change across diagnosis, treatment, and follow-up.

The National Cancer Institute describes cancer-related distress as physical, emotional, social, or spiritual strain that can make it harder to cope with cancer and its treatment. NCI also notes that distress may need attention at several points, including diagnosis, treatment, the end of treatment, remission, recurrence, or changes in the goal of care.

ASCO guidance on anxiety and depression in adults with cancer supports matching care to symptom severity and patient circumstances, with options that can include psychological, behavioral, and, when appropriate, pharmacologic treatment. These external sources provide context for the MDForLives findings. They do not replace the patient-reported survey data.

> **Methodology:** MDForLives Cancer Insight Survey, SGID 9017382. The supplied report contains 94 survey records, including 64 complete responses, across six countries. The care-status question had 66 responses, most core emotional-support questions had 65 responses, and country metadata had 93 responses. Fieldwork timing was not available in the supplied report. Internal operational fields are excluded from the analysis.

EXECUTIVE SUMMARY

Six signals that explain where emotional support succeeds and where patients still carry too much of the burden.

INSIGHT 01

61.5% Anxiety and persistent worry lead

Fear and ongoing worry are the most frequently reported emotional challenge after diagnosis.

INSIGHT 02

44.6% Patients often have to start the conversation

Distress was most often identified because patients raised their emotional concerns themselves.

INSIGHT 03

38.5% Treatment can become an access barrier

Treatment burden is the most frequently reported factor limiting emotional support.

INSIGHT 04

32.3% Unclear referral pathways block professional help

The path to professional emotional support is not always obvious or easy to enter.

INSIGHT 05

46.2% Continuity is possible, but not universal

Nearly half report support continuing through cancer care, while others describe support ending or never starting.

INSIGHT 06

35.4% Automatic referral is the leading improvement idea

Patients most often favor a system where distress screening leads directly to a referral step.

01

SECTION 01 · CARE JOURNEY

Emotional needs can appear at different points in the cancer journey

43.9% were receiving maintenance treatment or follow-up care.

CONTEXT

Cancer-related distress does not belong to one phase of care. A person can feel overwhelmed at diagnosis, during treatment, after treatment ends, or while waiting for follow-up results.

WHAT THE DATA SHOWS

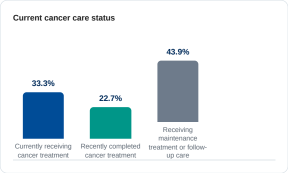
Among 66 respondents to the care-status question, 29 were receiving maintenance treatment or follow-up care, 22 were currently receiving treatment, and 15 had recently completed treatment.

THE INSIGHT

Because the survey spans active treatment, recent completion, and follow-up, later findings should be read as part of a changing journey rather than a single snapshot of one treatment stage.

WHY IT MATTERS

Support systems need to remain reachable as the source of distress changes. A patient who needs practical coping help during treatment may later need support around uncertainty, recovery, body changes, or fear of recurrence.


Current cancer care status

02

SECTION 02 · ANXIETY AND DISTRESS

Anxiety, fear, and persistent worry are the clearest emotional signal

61.5% selected anxiety, fear, or persistent worry as the emotional challenge that affected them most.

CONTEXT

A cancer diagnosis can introduce uncertainty about treatment, side effects, prognosis, family, work, finances, and what life may look like after treatment. Distress can also rise again around scans, changes in treatment, or new symptoms.

WHAT THE DATA SHOWS

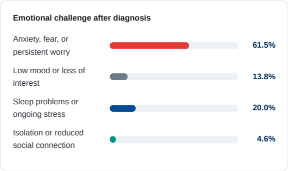
Anxiety, fear, or persistent worry was selected by 40 of 65 respondents. Sleep problems or ongoing stress followed at 20.0%, low mood or loss of interest at 13.8%, and isolation or reduced social connection at 4.6%.

THE INSIGHT

The dominant signal is not simply that patients feel worried. It is that worry can become the defining emotional challenge of the cancer experience for many people in this group.

WHY IT MATTERS

If emotional care is only offered after a patient reaches a crisis point, the system may miss a long period when support could already be useful. The NCI notes that distress can occur across different phases of cancer and may affect coping with treatment.


Emotional challenge after diagnosis

03

SECTION 03 · DISTRESS IDENTIFICATION

Patients are often the ones who have to say something first

44.6% say emotional distress was first identified because they raised their concerns themselves.

CONTEXT

Cancer teams can identify distress in several ways: routine screening, patient disclosure, observation by clinicians or caregivers, or follow-up after changes in treatment. The key difference is who carries the responsibility for starting the conversation.

WHAT THE DATA SHOWS

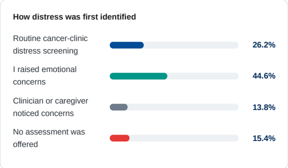
Twenty-nine of 65 respondents said they raised emotional concerns themselves. Seventeen reported routine cancer-clinic distress screening, nine said a clinician or caregiver noticed concerns, and ten said no assessment was offered.

THE INSIGHT

The strongest pathway in this sample depends on patient self-advocacy. That can work for people who feel able to speak up, but it may be harder for someone who is overwhelmed, unsure what is normal, worried about taking up clinical time, or simply does not know that emotional distress belongs in the cancer conversation.

WHY IT MATTERS

The NCI distinguishes brief distress screening from deeper psychosocial assessment. Screening can help identify who may need further support, but it only adds value when a clear next step follows.


How distress was first identified

04

SECTION 04 · FIRST SUPPORT

Peer support is the most common first step, but there is no single pathway

41.5% say a support group or peer program was the first emotional support offered.

CONTEXT

People can need different types of help. Some want to speak with someone who has lived through cancer. Others need structured therapy, medication, social-work support, or help with practical stressors. The first support offered may influence whether a person feels understood and whether they continue seeking help.

WHAT THE DATA SHOWS

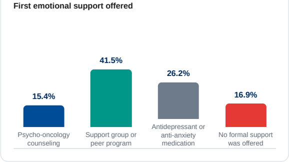
Support groups or peer programs were reported first by 27 of 65 respondents. Medication for anxiety or depression was reported by 17, psycho-oncology counseling by 10, and no formal support by 11.

THE INSIGHT

The data shows variety rather than a universal starting point. Peer support has a large role, but a meaningful minority begins with medical treatment or receives no formal support at all.

WHY IT MATTERS

ASCO guidance for anxiety and depression in adults with cancer supports matching treatment intensity and type to symptom severity and patient circumstances. The survey suggests that access to a range of options matters because needs are not identical.


First emotional support offered

05

SECTION 05 · ACCESS DURING TREATMENT

The effort of cancer treatment can make emotional care harder to reach

38.5% say treatment burden made access to needed emotional support difficult.

CONTEXT

Even well-designed support can fail if it requires another appointment, more travel, more paperwork, or more energy from someone already managing treatment and side effects. Access is not only about whether a service exists. It is also about whether the patient can realistically use it.

WHAT THE DATA SHOWS

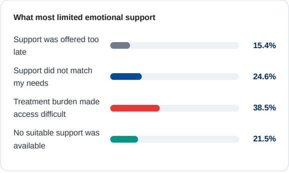
Treatment burden was the most frequently selected limitation, followed by support that did not match needs at 24.6%, no suitable support available at 21.5%, and support arriving too late at 15.4%.

THE INSIGHT

The most common barrier is built into the cancer journey itself. That makes integration important: support may work better when it is linked to the care pathway rather than operating as a separate system patients must navigate on their own.

WHY IT MATTERS

This is where convenience becomes part of quality. Flexible scheduling, virtual options, embedded services, and clearer coordination can reduce the extra work placed on patients.


What most limited emotional support

06

SECTION 06 · ESCALATION OF SUPPORT

When more support is needed, the next step is often clinical, but not always available

38.5% report psychiatry or medication support as the next step when additional emotional support was needed.

CONTEXT

First-line support may not be enough. Distress can intensify with side effects, prognosis changes, pain, sleep disruption, or new life stress. At that point, patients may need a different level or type of support.

WHAT THE DATA SHOWS

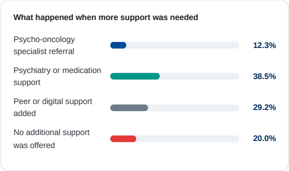
Psychiatry or medication support was reported by 25 of 65 respondents. Peer or digital support was added for 19, psycho-oncology referral for eight, and 13 said no additional support was offered.

THE INSIGHT

Escalation pathways exist, but they are uneven. One in five respondents reported no additional support even when more help was needed.

WHY IT MATTERS

A support system needs a way to step care up, not only a way to start it. Patients should know what happens if the first option is not enough, and clinicians need practical routes to refer onward.


What happened when more support was needed

07

SECTION 07 · WHAT DRIVES DISTRESS

Fear about the future sits beside fatigue, pain, and body-related changes

32.3% say recurrence or prognosis concerns affected their mental health most.

CONTEXT

Cancer-related mental health is shaped by both uncertainty and the physical realities of treatment. Fear of recurrence or progression can persist even when active treatment ends, while pain, fatigue, and changes to the body can influence mood and confidence day to day.

WHAT THE DATA SHOWS

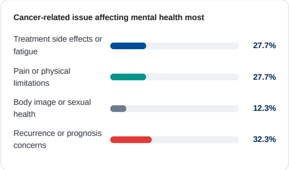
Recurrence or prognosis concerns were selected by 21 of 65 respondents. Treatment side effects or fatigue and pain or physical limitations were each selected by 18, while body image or sexual health was selected by eight.

THE INSIGHT

The emotional and physical parts of cancer are tightly linked. A person may not need the same support at every stage because the source of distress changes.

WHY IT MATTERS

Support plans that ask only whether distress exists may miss what is actually driving it. Understanding whether the main burden is fear, pain, fatigue, body image, relationships, or another concern can help direct the next conversation.


Cancer-related issue affecting mental health most

08

SECTION 08 · CONTINUITY AND ACCESS

Support can continue, but access often depends on finding the right doorway

46.2% say emotional support continued throughout cancer care, while 21.5% say no formal support was provided.

CONTEXT

Continuity matters because emotional needs do not necessarily stop when treatment ends. At the same time, even patients who want professional help may face unclear referral pathways, waiting times, cost, or practical treatment-related barriers.

WHAT THE DATA SHOWS

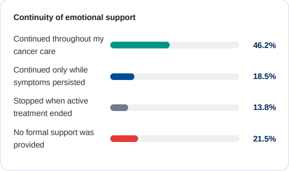
Thirty of 65 respondents said support continued throughout their cancer care. Fourteen reported no formal support. On a separate access question, 32.3% selected no referral or an unclear pathway as the leading barrier, followed by long waits at 26.2%, cost or insurance at 21.5%, and travel, time, or treatment burden at 20.0%.

THE INSIGHT

The gap is not only about service supply. Navigation matters. Patients may be more likely to use support when they know what is available, who can refer them, how long it may take, and what alternatives exist if one route is blocked.

WHY IT MATTERS

A continuous cancer pathway should include clear re-entry points for emotional support. Someone who declines support early may need it later, and someone whose support ends after active treatment may still face significant distress in follow-up.


Continuity of emotional support

09

SECTION 09 · IMPROVING THE MODEL

Patients favor a more automatic route from distress to help

35.4% say automatic referral after distress screening could most improve emotional support.

CONTEXT

Patients were asked which care model could most improve emotional support. Each option addresses a different failure point: recognizing distress, connecting to specialists, reducing appointment burden, or helping people navigate the system.

WHAT THE DATA SHOWS

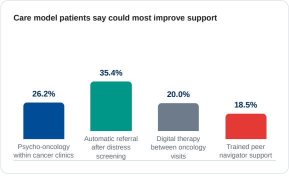
Automatic referral after distress screening led at 35.4%, followed by psycho-oncology within cancer clinics at 26.2%, digital therapy between oncology visits at 20.0%, and trained peer navigator support at 18.5%.

THE INSIGHT

The leading preference reduces the number of steps between being identified as distressed and getting help. That is consistent with other findings showing that patients often raise concerns themselves and can face unclear referral pathways.

WHY IT MATTERS

The practical opportunity is to connect recognition with action. Screening without referral can leave patients with the same navigation problem they had before the questionnaire was completed.


Care model patients say could most improve support

OPEN RESPONSE LENS

Patients describe uncertainty, missing support, and moments when care felt emotionally heavy.

The open-ended question asked patients to describe a time when cancer care affected their mental health and what support was missing. The responses were not formally coded, so this section does not assign percentages to themes. Instead, it highlights the kinds of experiences patients chose to describe in their own words.

Support that arrived late or not at all

Several responses describe needing psychological or social-work support that was unavailable, delayed, or never offered. One patient said chemotherapy caused severe anxiety and that counseling was not available.

Uncertainty about treatment and prognosis

Patients described fear while waiting between tests, uncertainty about whether treatment would work, and anxiety after learning that a current treatment was no longer effective.

Feeling emotionally unseen

Some responses describe feeling like a number, having to ask for options themselves, or wanting more opportunity to talk with someone who could address the emotional side of cancer.

Support from clinicians, family, or existing services

Not every response described a gap. Some patients said support was satisfactory or that nothing was missing, and one described meaningful support from an oncologist, hospital therapist, and family during a difficult period.

What the qualitative responses add: the same system can feel very different from one patient to another. Availability, timing, communication, and personal circumstances can change whether support feels accessible and useful.

PEOPLE ALSO ASK · TOPIC FAQ

Frequently asked questions about cancer and emotional support.

Is anxiety common after a cancer diagnosis?

Yes. Worry, fear, uncertainty, sleep problems, and low mood can occur at different points in cancer care. If these feelings are persistent, severe, or interfering with daily life, tell your cancer care team so they can discuss support options with you.

What is emotional or psychosocial support in cancer care?

It is support for the emotional, social, practical, and psychological effects of cancer. It can include counseling, psycho-oncology, support groups, peer programs, social work, medication when appropriate, and help with practical barriers that add to distress.

When should I tell my cancer care team about emotional distress?

You do not need to wait until distress becomes severe. You can raise concerns at diagnosis, during treatment, during follow-up, or whenever worry, low mood, sleep problems, fear of recurrence, or other emotional concerns begin to affect you.

What is psycho-oncology?

Psycho-oncology focuses on the emotional and psychological needs of people affected by cancer. Depending on the service, support may be provided by psychologists, psychiatrists, counselors, social workers, or other professionals who work with cancer teams.

Can emotional support continue after active cancer treatment ends?

Yes. Emotional needs can continue or change after treatment, especially during follow-up, recovery, surveillance, or periods of uncertainty about recurrence. Ongoing support should be based on what you need rather than on whether active treatment has ended.

What can I do if I do not know how to access cancer-related emotional support?

Ask your oncology team, nurse, primary care clinician, social worker, or hospital support service what referral options are available. If you are in immediate danger or having thoughts of self-harm, seek urgent help through local emergency or crisis services.

PATIENT SUPPORT LENS

What a more connected emotional-support journey could look like at four points in cancer care.

The survey suggests that the main opportunity is not one single therapy or service. It is a pathway that notices distress, explains options, reduces navigation burden, and stays available as needs change.

At diagnosis

Make emotional concerns discussable early. Explain that anxiety, fear, sleep problems, and low mood can be raised with the cancer team, and show patients where support begins.

During treatment

Reduce the extra work of getting help. Treatment burden can make separate appointments hard to manage, so embedded, coordinated, or virtual options can matter.

After active treatment

Do not assume distress ends when treatment ends. Follow-up can bring new worries about recovery, recurrence, body changes, work, family, and identity.

When distress increases

Make escalation predictable. Patients should know what happens if first-line support is not enough, including how to reach psycho-oncology, psychiatry, counseling, or other appropriate care.

CLOSING PERSPECTIVE

The most important improvement may be turning emotional support from a separate service into a visible part of the cancer pathway.

The survey does not suggest that every patient needs the same intervention. It suggests something more basic: patients need to know that emotional distress matters, that there is a legitimate place to raise it, and that there is a clear next step when they do.

That matters because the largest emotional signal in this survey is anxiety, fear, or persistent worry. Yet the most common way distress was first identified was not routine screening or clinician observation. It was patients raising their own concerns. At the same time, treatment burden was the leading limitation on support, and an unclear referral pathway was the leading barrier to professional emotional care.

Those findings fit together. When support depends on the patient recognizing distress, speaking up, finding the right service, arranging another appointment, and continuing to navigate cancer treatment at the same time, the system asks a great deal from someone who may already feel overwhelmed.

The preferred improvement, automatic referral after distress screening, offers one way to reduce that burden. Embedded psycho-oncology, digital therapy, and trained peer navigation address other parts of the same problem. The deeper opportunity is to build a connected pathway where screening leads to action, support can be stepped up when needed, and patients can re-enter support later if their needs change.

Screen, but connect the result to a next step

Recognition without referral leaves the patient with the same navigation problem.

Make support easier to use during treatment

Reduce extra travel, scheduling, paperwork, and fragmentation wherever possible.

Keep emotional care available after treatment changes

Support needs can return during recovery, follow-up, recurrence concerns, or changes in prognosis.

Offer more than one route

Peer support, counseling, psycho-oncology, digital care, medication, and social support can serve different needs.

Help future cancer-care insights reflect what the patient journey really feels like.

Join MDForLives to share your experiences and help shape a clearer understanding of emotional support, treatment burden, and life during and after cancer care.

Join the Panel

REFERENCES AND DATA SOURCE

1. MDForLives internal survey report. All Markets Report for SGID 9017382, Project: Engagement Campaign | Cancer Insight Survey.
2. National Cancer Institute. Adjustment to Cancer: Anxiety and Distress (PDQ®), patient and health professional versions.
3. Andersen BL, et al. Management of Anxiety and Depression in Adult Survivors of Cancer: ASCO Guideline Update. Journal of Clinical Oncology. 2023.

External sources provide clinical context only. All percentages and response counts attributed to MDForLives come from the supplied Cancer Insight Survey report.

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