Friends of Max
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www.friendsofmax.info

Long Term Medication Impact Survey

Conducted by Friends of Max (FOM) to commemorate World CML Day 2026

Exploring and gaining insights from the lived experience of patients (members of FOM) on life long treatment for CML and GIST.

Introduction

We are at an important milestone in the journey of CML and GIST support.

Friends of Max (FOM), which began as a patient support network, today has grown into a powerful entity connecting patients, caregivers, physicians, volunteers and advocates across the country and globally. Over the last quarter century, the story of TKIs and FOM have become inseparable.

On this momentous occasion marking World CML Day 2026, we present to the global CML community and to the world at large, learnings from patients and their families based on a quarter century of living with CML.

Responding to an in house survey, City Chapter Leaders from across India, both patients and caregivers themselves, have shared various aspects of their experience of living with CML/ GIST and of being a part of the FOM family.

A total of 532 responders representing both urban and rural India agreed to undertake the survey.

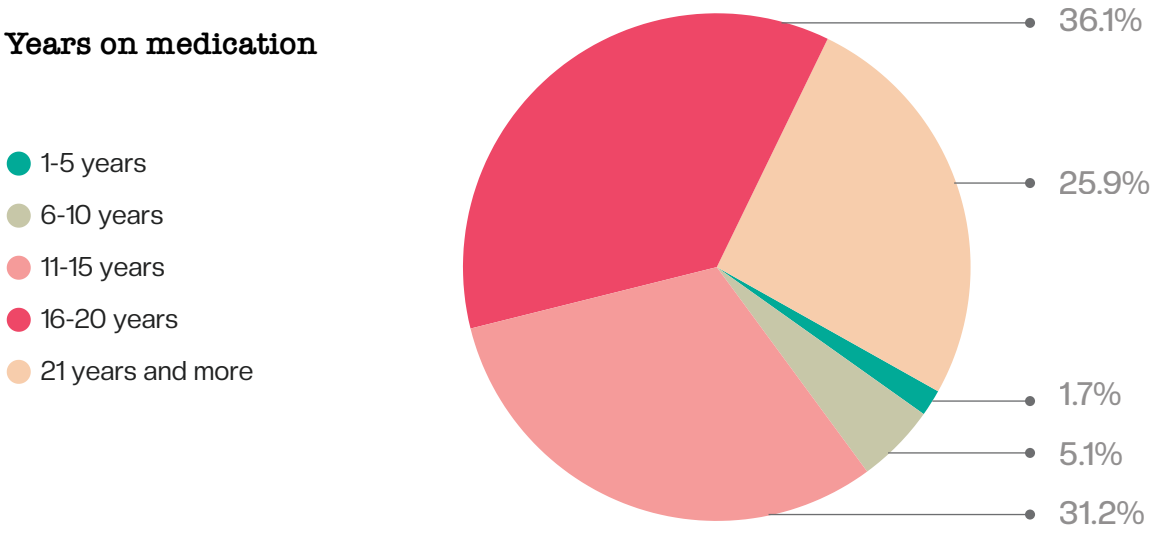
This report is a reflection of their voices.

We remain grateful to every respondent who took time to participate and share their experiences.

Survey at a glance

Indicator	Survey finding
Total Respondents	532
Female respondents	32.5%
Male respondents	67.5%
Age range of respondents	20-80+ years
CML patients	513 (96.4%)
GIST patients	4 (0.8%)
Caregivers	15 (2.8%)
FOM members	91.70%

Years on medication



The survey represents a predominantly long-term treatment population:

In total, **93.2% of respondents have been on medication for more than 10 years**, providing a particularly valuable perspective on the realities of long-term treatment.

Living with long term treatment: Some key findings

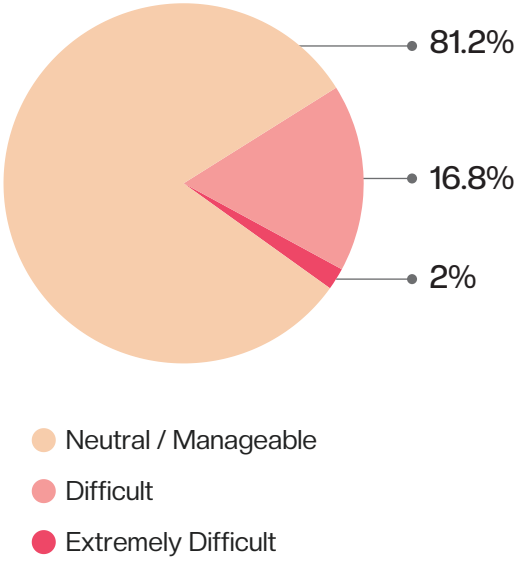
A. How difficult has it been to be on lifelong treatment?

81.2 % of the responders felt it to be manageable and neutral

This is probably one of the most significant findings of the survey – For a majority of the respondents, long-term treatment has become a manageable part of their daily lives.

This is an important reflection of how timely and seamless access (provided by The Max Foundation and Friends of Max) to medicine and monitoring, emotional and practical support, reliable information and expert medical care have helped patients and their families successfully navigate their journey on life long treatment. For many respondents today, taking their daily medication, undergoing regular BCR ABL testing, staying informed about their disease and consulting expert physicians over many years is no longer an insurmountable burden; it has become an integral part of their daily routine.

However, "manageable" does not mean "without challenges."



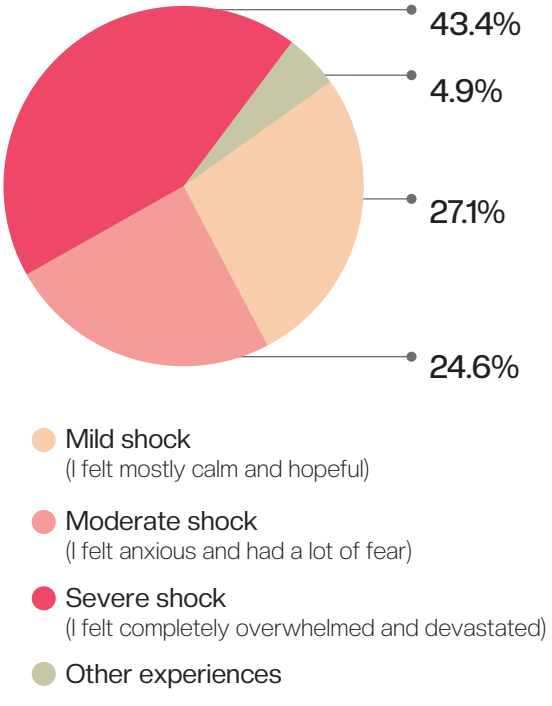
B. How emotionally overwhelming (shocking) was it when you first received the news about your cancer diagnosis?

43.4 % of the responders felt severe shock, anxiety and fear when they first received their cancer diagnosis.

While living with long-term treatment may have eventually become manageable, the initial cancer diagnosis remains a deeply traumatic and emotionally overwhelming experience.

This finding highlights the importance of the period immediately following diagnosis. Newly diagnosed patients and their families of course need immediate access to the best treatment under expert physicians from reputed institutions but equally important, they also need timely information, reassurance, emotional support and guidance to help them understand and navigate the arduous journey ahead.

Support, therefore, needs to begin at the point of diagnosis and continue throughout the treatment journey, rather than focusing solely on medical care.



C. How difficult has compliance been?

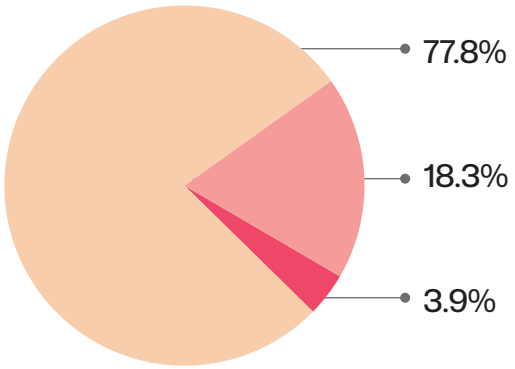
77.8% have found this very easy, reporting that they rarely or never miss a dose and their doctor's scheduled appointment.

This is a strong and positive finding. Long-term medication is most effective when patients are able to take their medicines as prescribed and follow up regularly with their treating physicians.

The importance of good adherence behaviour and compliance is continuously reiterated through various patient intervention channels be it the monthly Patient Support Group Meetings, periodic messaging on SMS and WhatsApp groups and disbursement of disease information material. The survey findings suggests this resonates deeply with the patients and their families and has had a very positive impact on adherence to medication protocol.

For many, taking their medication regularly and staying connected with their treating physicians have become an established part of their daily routine, and one that they continue to maintain throughout their treatment journey.

Majority have successfully incorporated treatment into their daily lives.



- Very Easy
  (I rarely or never miss a dose and my doctor's appointment)
- Moderate
  (I occasionally struggle or miss doses and my doctor's appointment)
- Very Difficult
  (I frequently struggle to take my medication on time and go for my doctor's appointment)

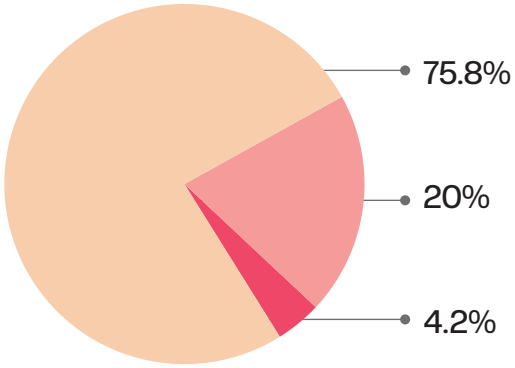
D. How difficult has compliance with monitoring been?

75.8% responded very easy, rarely missing their BCR ABL test as and when recommended by their doctor.

This demonstrates that many have access to regular monitoring and so it has become an integral part of their long-term treatment routine.

However, at the same time, the finding that 20.1% experience some level of difficulty with monitoring also highlights an important gap. Access is still affected by cost, availability and practical challenges.

It is an important reminder that there is **urgent need for greater support from partners and stakeholders to strengthen programs like FOM's Home-based Diagnostic Testing initiative provided at no cost to patients. Increased funding and wider outreach can help make critical monitoring more accessible and ensure that no patient is left without access to essential BCR-ABL testing which is vital for positive outcomes.**



- Very Easy
  (I rarely miss my BCR ABL test as recommended by my doctor)
- Moderate
  (I miss my BCR ABL test as recommended by my doctor)
- Very Difficult
  (I frequently struggle and miss my BCR ABL test as recommended by my doctor)

E. What are the major difficulties that you faced?

Despite high levels of accurate and timely treatment as well as compliance in monitoring, respondents identified several over riding challenges. This establishes the undeniable fact that that **successful long-term cancer care is multidimensional.**

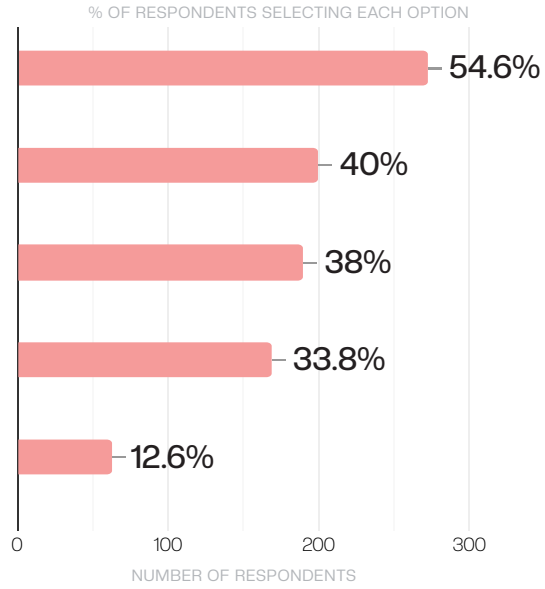
Managing medication side effects:
this has emerged as the single largest challenge having a significant impact on the quality of life.

Balancing work, family and treatment schedules:
Appointments, tests and medication routines must be balanced alongside employment, family responsibilities and other commitments.

Financial burden or high cost of tests/medicines and travel costs
still remains a major concern particularly for patients whose treatment remains lifelong.

Emotional stress, stigma, fear, anxiety or depression:
The emotional burden of living with cancer does not necessarily disappear once treatment becomes routine. Fear, anxiety, stigma and uncertainty remain part of the experience for many.

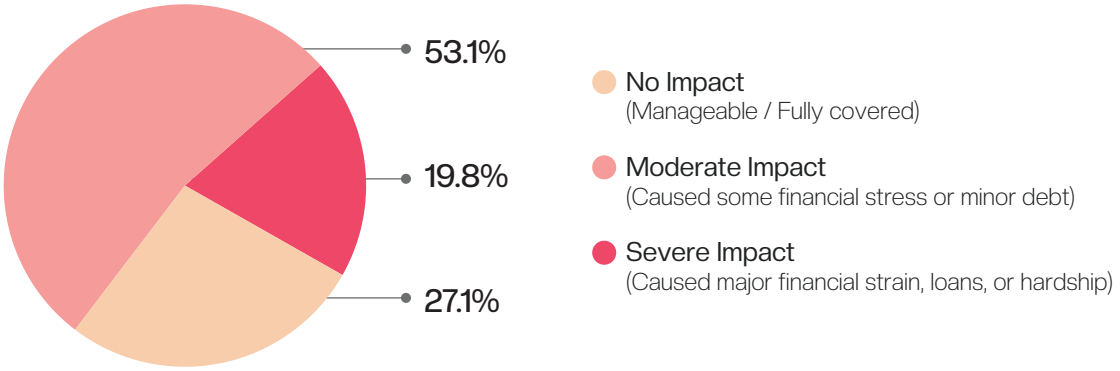
Lack of access to local doctors or specialized care:
Although this was reported by a smaller proportion of respondents, it highlights an important geographic and healthcare-access challenge, particularly for people living in rural and remote areas.



Medication alone is not enough; patients also need support to manage side effects, emotional well-being, family & work responsibilities and finances in order to achieve all round, comprehensive and long term care.

F. Financial toxicity: How difficult did you find it to manage your finances when diagnosed and later.

72.9% of respondents experienced at least some financial impact.



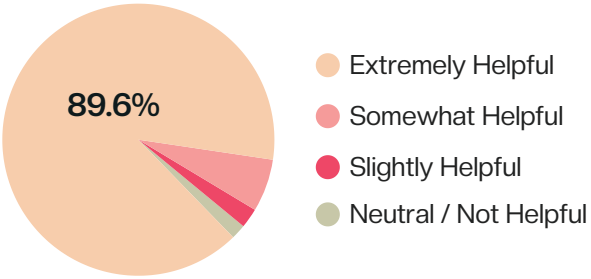
Financial toxicity continues to remain a major challenge long after diagnosis for patients on lifelong treatment.

G. How beneficial has being a member of Friends of Max (FOM) been for you?

Perhaps one of the strongest findings of the survey providing a meaningful validation of the role that FOM plays in the lives of patients and their families:

89.6% said that being an FOM member has been extremely helpful.

It reinforces that support beyond medicine is critical and being a part of a community is perhaps as important as access to treatment itself.



H. What benefit of being a member of Friends of Max (FOM) has been most valuable to you? What FOM means to patients?

Respondents identified several benefits as particularly valuable.

Companionship: Connecting with other patients who share similar experiences was the most valued benefit.

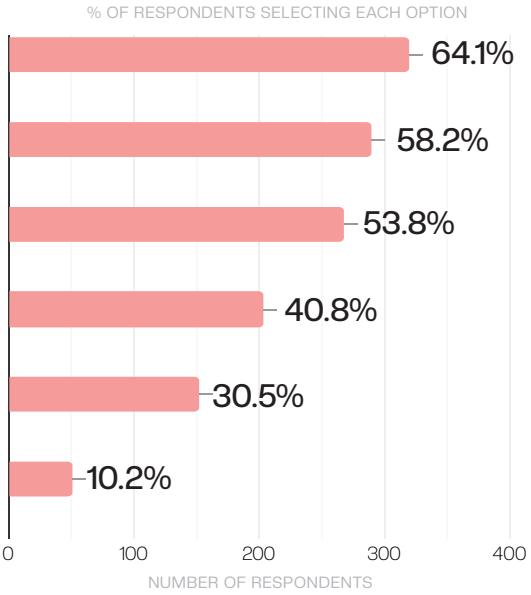
Understanding: Having a safe space where my disease and challenges are truly understood was also much valued by the respondents.

Membership & Guidance: They valued access to patient meets, Medical sessions and disease related materials.

Access to regular BCR ABL testing: Home based monitoring tests at no cost or at FOM preferred pricing.

Patient's voice: Appreciated a chance to be heard, ask questions, be able to participate and share their story

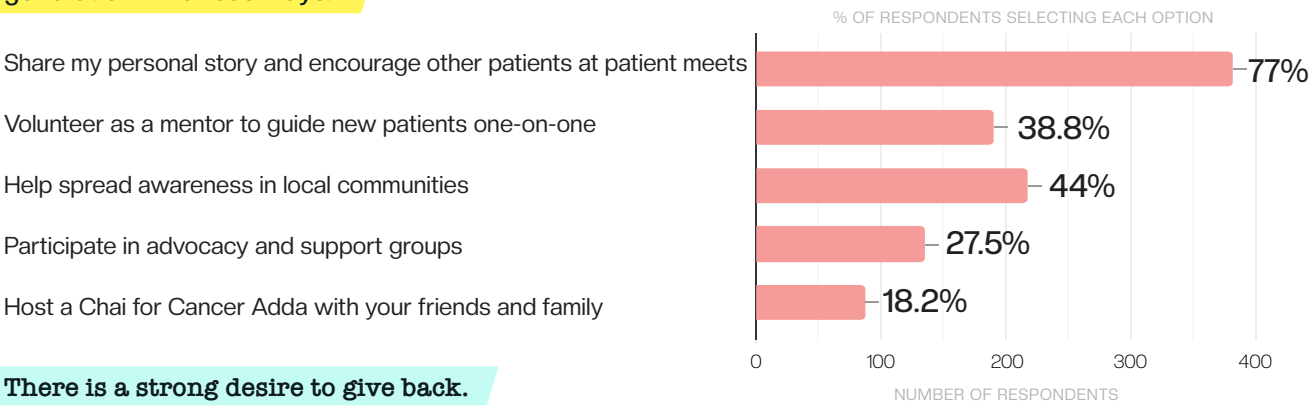
Access to Education: Respondents identified financial aid towards the schooling costs of self or their dependents through Project Shiksha as a valuable benefit they get from FOM.



I. How do you want to give back to the next generation of CML and GIST patients?

One of the most encouraging findings is that many respondents do not see themselves only as recipients of support.

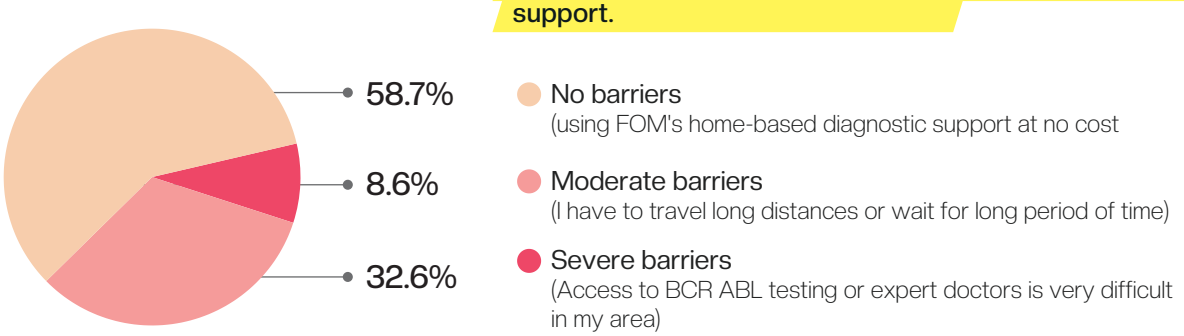
They want to become a source of support for the next generation in various ways:



There is a strong desire to give back.

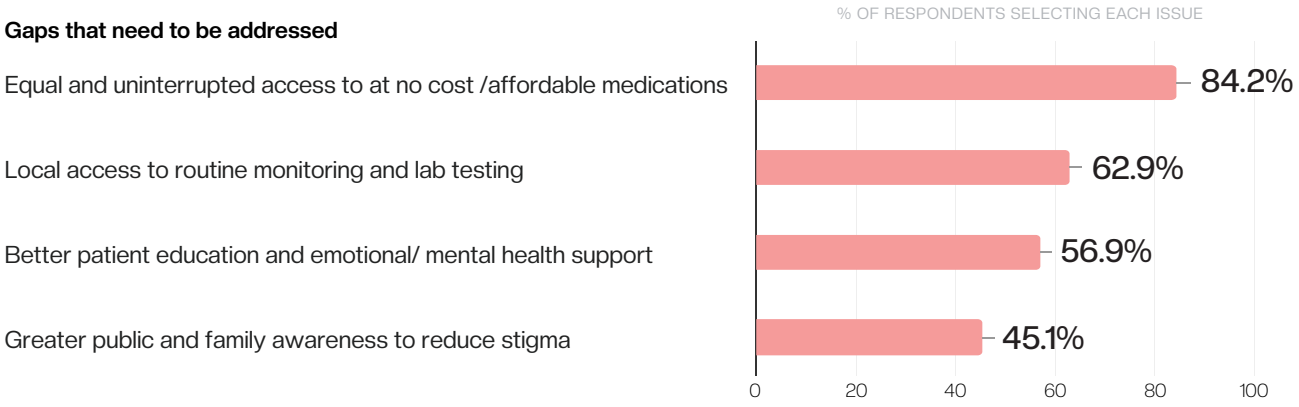
J. Do you face any systemic barriers in getting your routine health checks and diagnostic monitoring?

58.7% of respondents face no systemic barriers explicitly because they utilize FOM's free home-based diagnostic support.



The study shows that FOM's home-based essential BCR-ABL testing at-no cost to patients is successfully solving the primary logistical challenge for the majority of patients.

K. In your opinion, what is the biggest gap that needs to be addressed so that "No CML/GIST Patient is Left Behind"?



84.2% of respondents identified equal and uninterrupted access to free or affordable medications as the top priority.

However, the findings also highlight that to ensure "No CML/GIST Patient Is Left Behind", especially where treatment is long-term, it requires a comprehensive approach that goes beyond medication availability alone. Patients need affordable and uninterrupted access to treatment, accessible local monitoring and laboratory testing and adequate information and emotional support throughout their care journey.

It reinforces the need to address both access to treatment and the broader patient-support ecosystem, rather than focusing on medication availability alone for patients on long term medication.

Conclusion:
What does the survey tell us

1. **Long term treatment has become a lived reality**, despite a diagnosis that once brought severe shock, fear and uncertainty.

2. While treatment is manageable for most, **side effects, financial pressures, emotional challenges and competing responsibilities remain a significant challenge for many.**

3. **Patients show a high degree of engagement with their treatment** showing high levels of compliance and adherence.

4. **Financial toxicity still remains a major issue** for most of the respondents.

5. **FOM provided safe and secure platform matters enormously to majority**; peer support, companionship and understanding were judged as the most valued benefits of FOM membership.

6. **Access to monitoring remains uneven with systemic barriers** continuing to affect a significant minority. An urgent need to work with donors and stakeholders to break these barriers.

7. **Patients want to give back:** Their willingness to share their stories, mentor new patients, spread awareness and participate in advocacy represents an important opportunity waiting in the wings.

8. **Leverage the willingness and rich experience of patients accumulated over 10, 15, 20 or more years of treatment as a rich repository of knowledge, resilience and hope for newly diagnosed patients and their families.**