ONE CANCER AT A TIME

Acute Lymphoblastic Leukemia (ALL)

Maintenance Phase Guide

For Parents & Caregivers





"Maintenance Phase:
The Superhero's Shield After The Big Battle !"

CANKIDS KIDSCAN
National Society for Change for Childhood Cancer in India

FOREWORD

Every family beginning the journey of treating Acute Lymphoblastic Leukemia (ALL) enters a world of new words, new routines, and many emotions. After the difficult first months of treatment, when a child or young person begins to look and feel better, families often feel relief — and sometimes, confusion about what comes next.

Yet the maintenance phase is one of the most important parts of treatment. Most children look well during this time, but the medicines taken at home every day are crucial to preventing relapse and ensuring cure.

This guide has been created for you — parents, caregivers, and teenage and young adult (TYA) patients — to make the maintenance phase clearer, easier, and more predictable.

Developed through the One Cancer at a Time (OCAT–ALL) initiative of CanKids… Kidscan and aligned with the WHO Global Initiative for Childhood Cancer, this guide:

- explains why each part of maintenance therapy matters
- provides easy-to-follow instructions for daily and weekly routines
- includes diaries, reminders, and symptom trackers
- helps you stay connected with your medical team
- supports teenagers and young adults in taking charge of their own treatment safely

It is also an important tool for your treating doctor and the entire care team, helping them monitor adherence, understand challenges at home, and guide you through each stage of treatment with greater precision and confidence.
We Wish you all the best for your journey.

Team OCAT, CanKids KidsCan

Patient Basic Information Sheet

Patient Name:

Age: **Age at Diagnosis:**

Diagnosis:

Treating Centre:

Treating Consultant:

Date of Starting Rx: / /

Date of Starting Maintenance Rx: / /

Contact no. of Rx Team:

ALL Diary: Maintenance Treatment

Dear Parent/Caregiver,

You've shown an incredible strength to come this far and now your child's journey enters a new and a hopeful stage the MAINTENANCE PHASE. After the challenging and overwhelming first few months of treatment for Acute Lymphoblastic Leukemia (ALL), your family has reached to a gentler chapter, one focused on healing, resilience, and moving forward together in this journey.

What is the Maintenance Phase?

Your child's disease is well controlled. The maintenance phase aims to maintain this disease control and eventually cure the disease, this phase lasts for 2 years or more. While your child appears well, continuing treatment is essential to prevent relapse — a silent risk even when no cancer is visible. This treatment is gentler but as important as the intensive phase.



What Will This Phase Involve?

All patients will receive:

- 6-Mercaptopurine (6-MP) – Taken daily at night. The dose is adjusted as per CBC report of your child
- Methotrexate (MTX) – Taken orally once a week
- Intrathecal Methotrexate – via lumbar puncture every 12 weeks

In addition, some units may give:

- Vincristine (VCR) – Monthly in hospital
- Steroids (like Dexamethasone) – 5-day pulses with Vincristine



- Each medicine plays a vital role in keeping leukemia away
- Blood tests and clinic visits continue as per the treatment calendar given by your medical team.

01 Why Maintenance is so Important ?

- It Prevents relapse by targeting hidden cancer cells
- Missed doses can increase the chance of relapse.
- Adherence is your child's lifeline to cure

02 Can My Child Attend School?

- Yes, your child can attend school regularly and participate in all activities



03 Your Role As A Parent Is Invaluable

- You're not just giving medicines, you are giving hope, life, and the chance to heal completely.
- You may need to explain the importance of this continuing treatment to your child and to your family.

04 Tips for This Journey

- Keep a treatment calendar or diary
- Regular blood tests as advised
- Communicate with your medical team
- Ensure school and activity participation of your child and support them emotionally



05 Missed Dose + Daily 6-MP Reminder

- If a dose is missed, inform your healthcare team.
- Keep a clearly visible reminder - for example, on the fridge, wall or table - so that you do not miss any 6-MP doses.

06 Track Medicine

- Set a daily alarm or medicine reminder to help build a routine and avoid missed doses.
- Parents/caregivers should supervise each dose and ensure that the child actually takes the medicine.

07 Fever / When to Contact Hospital

- Most infections are mild, but consult your medical team.
- CBC and, if required, antibiotics may be advised by the treating team.

08 Dietary Guidance

- Only hygiene-related restrictions are needed.
- Avoid supplements unless prescribed by your medical team.
- Avoid consuming milk one hour before and one hour after meals.

09 Hair Loss

- No, usually there is no hair loss in this phase, but some children may have mild hair fall periodically.

10 Vaccination

- Vaccination During Maintenance Killed vaccines can be given.



Remember

- **You're not alone — the medical team and other parents are with you.**
- **This is the final stretch — and it matters.**
- **Let's walk it together, with care, courage, and commitment.**

NEED HELP OR SUPPORT?

Contact your Care Coordinator or Medical Team !

DANGER SIGNS DURING MAINTENANCE

01 Child Still Needs Chemotherapy

Your child still needs to take chemotherapy medicines during the maintenance phase.



02 Contact Your Medical Team Immediately If Your Child Has:

- Fever or chills
- Difficulty in breathing or weakness
- Persistent vomiting or diarrhoea
- Severe abdominal pain
- Unusual bleeding or bruising
- Severe headache, confusion, seizures or unsusual sleepiness
- Yellowing of the eyes or skin
- Very poor intake or signs of dehydration
- Any sudden or concerning change in your child's health condition.



CONTACT YOUR MEDICAL TEAM IMMEDIATELY

DOCTOR'S PRESCRIPTION



DOCTOR'S PRESCRIPTION



DOCTOR'S PRESCRIPTION



DOCTOR'S PRESCRIPTION



DOCTOR'S PRESCRIPTION



DOCTOR'S PRESCRIPTION



DOCTOR'S PRESCRIPTION



DOCTOR'S PRESCRIPTION



CALENDAR

JANUARY

SUN	MON	TUE	WED	THU	FRI	SAT
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

FEBRUARY

SUN	MON	TUE	WED	THU	FRI	SAT
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28

MARCH

SUN	MON	TUE	WED	THU	FRI	SAT
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15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Monitoring & Dose Adjustment Calendar – Maintenance Phase

Date	Hb (g/dL)	TLC ($\times 10^9$/L)	Plt. Count ($\times 10^9$/L)	N (%)	L (%)	M (%)	6-MP Dose (mg)	New Dose (mg)	MTX Dose	Notes

CALENDAR

APRIL

SUN	MON	TUE	WED	THU	FRI	SAT
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12	13	14	15	16	17	18
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26	27	28	29	30		

MAY

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24	25	26	27	28	29	30

JUNE

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21	22	23	24	25	26	27
28	29	30				

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CALENDAR

JULY

SUN	MON	TUE	WED	THU	FRI	SAT
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AUGUST

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30	31					

SEPTEMBER

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20	21	22	23	24	25	26
27	28	29	30			

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CALENDAR

OCTOBER

SUN	MON	TUE	WED	THU	FRI	SAT
				1	2	3
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NOVEMBER

SUN	MON	TUE	WED	THU	FRI	SAT
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15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30					

DECEMBER

SUN	MON	TUE	WED	THU	FRI	SAT
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AFTER MAINTENANCE PHASE COMPLETION

01

Your child still needs to take chemotherapy medicines during the maintenance phase.



02 AN IMPORTANT MILESTONE

- Congratulations on completing your MP.
- Completing MP is an important milestone in your child's treatment journey.
- Treatment should be stopped as advised by the treating team.
- Continue regular follow-up.
- Continue education.
- Maintain a healthy lifestyle.



03 YOUR FOLLOW-UP PLAN



Next Appointment :	
Next Blood Test :	
Treating Centre :	
Follow-Up Schedule :	



ONE MILESTONE COMPLETE – CONTINUE WITH CARE, CONFIDENCE AND REGULAR FOLLOW-UP.

CANKIDS KIDSCAN

National Society for Change for Childhood Cancer in India



We gratefully acknowledge our OCAT–ALL Advisory, whose national and international expertise shaped this initiative

Children with Cancer Can Survive And Thrive

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