ICCI
Indian Childhood Cancer Initiative

Indian Guidelines for Psychosocial Care in Paediatric Oncology



Developed by the Psychological and Social Support Task Force
Indian Childhood Cancer Initiative (ICCI)

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Quick Reference Guide

This document collates abridged, quick-reference visual summaries for all eight domains of the Indian Guidelines for Psychosocial Care in Paediatric Oncology. Each summary presents the core framework of the respective domain, including screening approaches, tiered care pathways, and key action points.

Detailed assessment tools, comprehensive protocols, worked case examples, and appendices are provided in the complete guideline document and are available on request.

For the complete guideline document, please contact the guideline working group / corresponding author.

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Introduction

About This Guide, Core Principles & How to Use It

Psychosocial care is an essential part of comprehensive pediatric oncology care (Wiener et al., 2014). Although 5-year survival now exceeds 85% (Chow et al., 2020; Siegel et al., 2024), childhood cancer continues to impose substantial emotional, social, developmental and financial challenges on children and families across diagnosis, treatment, survivorship, relapse and end of life (Kazak & Noll, 2015; Pelletier & Bona, 2015; Nipp et al., 2017; Weaver et al., 2015). In India, psychosocial services have expanded in recent years but remain fragmented and unevenly distributed across institutions and regions, and dedicated pediatric psycho-oncology services and professionals remain scarce (Daruvala et al., 2025; Deodhar et al., 2022; Satapathy et al., 2018).

These guidelines were developed by the **Psychological and Social Support Task Force of the Indian Childhood Cancer Initiative (ICCI),** established in response to the WHO Global Initiative for Childhood Cancer. They build on the Task Force's national position statement (Daruvala et al., 2025), which called for national guidelines to ensure standardised and equitable access to psychosocial care in pediatric oncology centres across India and were informed by a nationwide priority and feasibility exercise with healthcare professionals, psychosocial providers, non-governmental organisations, advocacy groups and people with lived experience. The guidelines offer an adaptable, scalable framework that institutions can implement progressively according to local resources.

Intended users: Pediatric oncologists, psycho-oncologists, psychologists, psychiatrists, social workers, nurses, counsellors, child life specialists and other allied health professionals and hospital administrators, programme planners, policymakers, non-governmental organisations, advocacy groups and survivor networks that plan or support psychosocial services.

The Three-Tier Model of Care

Every domain follows the Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak et al.), which matches the intensity of support to each family's level of need:

UNIVERSAL	TARGETED	ADVANCED / CLINICAL
All children and families: basic psychosocial support, routine screening, information and supportive care	Families with elevated risk, adjustment difficulties or emerging concerns that need support beyond universal care	Significant psychological distress, mental health concerns or complex challenges that need specialised care

Tiering allocates resources efficiently, gives each family care in proportion to its need, and allows services to be scaled up progressively in resource-limited settings.

How to Use This Guide

1. Each domain opens with an overview and an At a glance summary, followed by numbered sections, Quick Action boxes and 10 Key Action Points.

2. Quick Action boxes are colour-coded by level of care:
   - **Green** Universal (all children, adolescents and young adults and families).
   - **Purple** Targeted (identified need).
   - **Pink** Advanced/Clinical or urgent escalation.

3. ◆ marks interventions that require a trained psychosocial or mental health professional (Targeted and Advanced/Clinical levels).

4. Abbreviations are spelt out at first use in each domain, so each domain can be read on its own.

5. Each domain is a summary. The full guideline, with complete tools, protocols and appendices, is available on request from the corresponding author (daruvala91@gmail.com).

Core Principles - Across All Domains

Eight principles underpin every domain (also consider developmental stage, safeguarding, consent/assent and privacy):

CHILD & FAMILY-CENTRED
Address the needs of children, parents, caregivers and siblings.

MULTIDISCIPLINARY COLLABORATION
Integrate psychosocial care into routine oncology services through team working. and siblings.

CULTURAL & CONTEXTUAL SENSITIVITY
Respect beliefs, family structures, socioeconomic realities and community context.

EQUITY & ACCESSIBILITY
Make care accessible across all settings, including resource-limited ones.

CONTINUITY OF CARE
Support at every stage- diagnosis, treatment, relapse, survivorship, palliative care, bereavement.

CAPACITY BUILDING
Trained professionals, structured training, supervision and ongoing development.

SUPPORT FOR FAMILIES AND PROVIDERS
Care for caregivers, siblings and staff to promote wellbeing and prevent burnout.

EVIDENCE INFORMED PRACTICE
Grounded in available evidence and adapted to the realities of practice in India.

Adolescents & Young Adults (AYA) Across All Domains

Adolescents and young adults (AYAs) have distinct developmental needs, including identity, autonomy, body image, peer relationships, sexuality and fertility, education and career, and future planning (Zebrack & Isaacson, 2012; Ferrari et al., 2021; Oktay et al., 2018). Involve them in decisions in line with their age and wishes and, where appropriate, offer time to speak without parents present (Weaver et al., 2015; Committee on Bioethics, 2016; Smith et al., 2016). Young adults may need adult-oriented services and different family arrangements from younger patients (Ferrari et al., 2021; Coccia et al., 2018).

Domain	Adolescent & young adult considerations
1 Evaluation, Triage & Referral	Offer confidential time; screen for mood, body image concerns , substance use (CRAFFT) , risk behaviours and others with age-appropriate tools.
2 Interventions	Use peer support and age-appropriate psychological therapies (e.g., CBT)supportive psychotherapy; respect privacy; use digital formats where suitable.
3 Workforce & Training	Train staff in adolescent communication, confidentiality, and consent and assent.
4 Siblings & Caregivers	Adolescent siblings may take on caregiving roles - watch for emotional and school impact.
5 Survivorship & Reintegration	Plan for education and career, fertility concerns, relationships and health behaviours; prepare early for transition to adult care, survivorship care and after completion of treatment clinics.
6 End of Life & Bereavement	Involve adolescents and families in advance care planning according to their wishes and capacity; support legacy-making.Identify at risk families for complicated bereavement.
7 Staff Support	Recognise the particular emotional impact of caring for adolescents and young adults; include it in supervision and debriefing.
8 Hematopoietic Stem Cell Transplant	Address identity, body image, isolation from peers and future planning; maintain digital peer connection during isolation.

How These Guidelines Were Developed

A national consultative meeting of hospitals, civil society organisations, survivor and advocacy groups and psychosocial professionals, with international expert advisors Dr Valerie Crabtree, Dr Lori Wiener and Dr Viviana Trigoso, identified the key domains. A working group drafted each domain from national and international guidance adapted to Indian contexts; drafts were reviewed by the international experts, working group and a wider stakeholder group.

Important note: Much of the evidence comes from high-income countries; India-specific research remains limited and is a priority. These guidelines are a framework, not a prescriptive model, and do not replace clinical judgement or institutional policies- adapt them to local resources, culture, language and the needs of each child and family.

Domain 1

Evaluation, Triage and Referral

This section covers three linked components of psychosocial care:

EVALUATION
Systematic identification of psychosocial needs through clinical observation, interviews, and screening tools.

TRIAGE
Prioritising identified needs and risks, and matchingChildren, Adolescents and Young Adults (CAYA) and families to the appropriate level of psychosocial care.

REFERRAL
Connecting CAYA and families with appropriate internal or external services.

At a glance:

1. Evaluation is a shared Multidisciplinary Team (MDT) responsibility, beginning as early as possible after diagnosis and repeated at key transition points.

2. A three-tier triage model (Universal → Targeted → Advanced/Clinical) matches the intensity of psychosocial care to the level of need based on the Pediatric Psychosocial Preventative Health Model (PPPHM) by Anne Kazak, 2006.

3. Clear referral pathways both in-house and externally facilitate timely access to specialised psychosocial and mental health services.

1.1 Evaluation - Who, When, How

WHO EVALUATES

Shared responsibility of the MDT. Initial concerns may be identified by doctors, nurses, psycho-oncologists, and social workers.

Complex or significant concerns - e.g., suicidal thoughts or self-harm, suspected abuse, severe or persistent distress, or a suspected mental health disorder - should be assessed by appropriately qualified psychosocial or mental health professionals.

WHEN TO EVALUATE

As early as possible after diagnosis. Reassess at key transition points, including treatment completion, progression, relapse, & survivorship.

Repeat assessment whenever new concerns emerge.

HOW TO EVALUATE

Clinical observation and discussion with CAYA and caregivers.

Use standardised general and condition-specific screening tools where appropriate.

Assessments may include distress, family functioning, financial hardship, and suicide/self-harm risk.

For children with brain tumours, include neuropsychological evaluation.

Key psychosocial domains & example tools

These are representative examples only. The full guideline includes more than 25 validated tools across 7 psychosocial domains, with information on languages, age ranges, and administration and interpretation.

Domain	Example tool	Age	Tier
Anxiety	Child Behaviour Check List (CBCL), Achenbach System of Empirically Based Assessment (ASEBA), Patient-Reported Outcomes Measurement Information System (PROMIS) Anxiety	1.5–18 yrs	Targeted / Clinical
Depression & mood	Pediatric Quality of Life Inventory (PedsQL) Cancer Module	2–18 yrs	Targeted / Clinical
Emotional & adjustment	Strengths & Difficulties Questionnaire (SDQ)	5–17 yrs	Universal

Domain	Example tool	Age	Tier
Behavioural concerns	Child Behaviour Check Lisk (CBCL), Pediatric Symptom Checklist (PSC)	4–18 yrs	Universal / Targeted
Sleep disturbance	Sleep Disturbance Scale for Children (SDSC)	3–18 yrs	Targeted / Clinical
Self-harm & suicide risk	Columbia Suicide Severity Rating Scale (C-SSRS)	6+ yrs	Targeted / Clinical
Developmental delay	Ages & Stages Questionnaire (ASQ-3)	1–5.5 yrs	Universal
Substance use (adolescents)	Car, Relax, Alone, Forget, Friends, Trouble (CRAFFT) version 2.1	12–21 yrs	Universal – Clinical

*Age ranges and recommended use may vary according to the specific version, informant, language, and clinical context. Refer to the full guideline for administration and interpretation details.

Quick action - Positive psychosocial screen

A positive screen should prompt clinical review rather than a diagnosis based on the screening tool alone.
Clarify the concern, assess severity and functional impact, identify immediate safety concerns, discuss findings with CAYA and caregivers as appropriate, and determine the need for targeted intervention, specialist assessment, or referral. Document findings. Schedule follow-up as per severity.

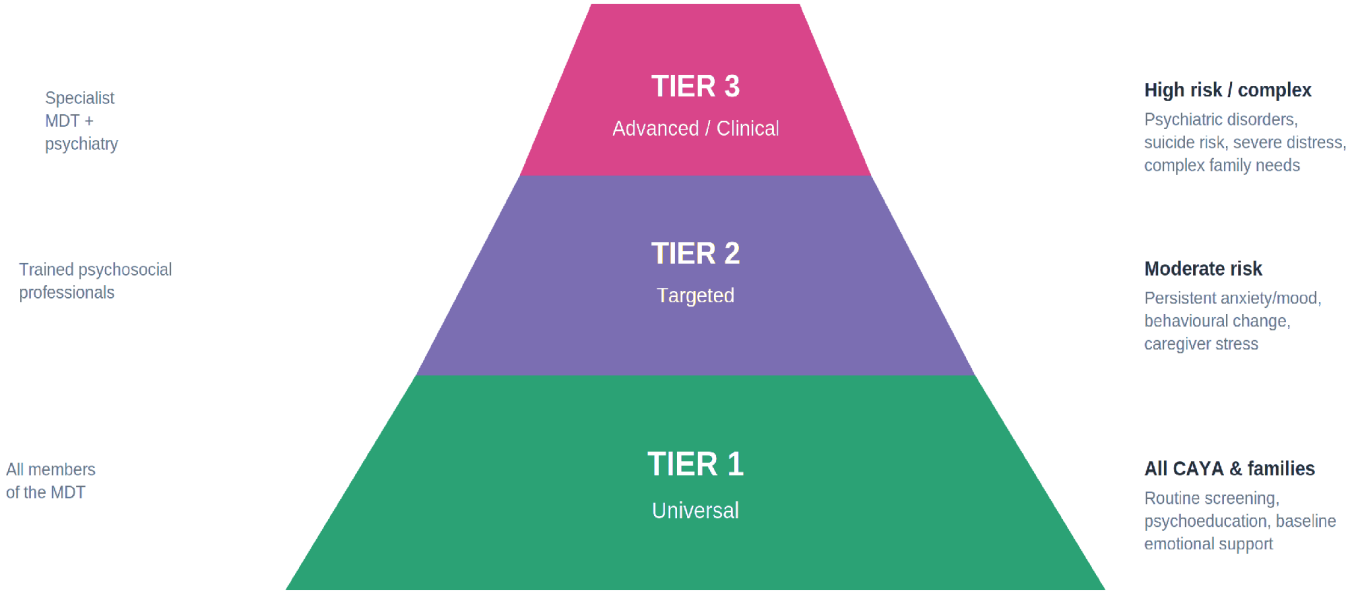
⚠ Screening tools are not diagnostic instruments. They flag concerns that need further clinical exploration - a positive screen always needs clinical review.

Special risk domains - quick reference

Risk	What to look for / ask	How to respond	When to refer / escalate
TREATMENT NON-ADHERENCE / ABANDONMENT	Missed appointments, treatment interruptions or refusal, financial or travel difficulties, misconceptions about treatment, consideration of alternative therapies.	Explore concerns and treatment understanding; give clear, age-appropriate information. Assess and address barriers; involve social work and the medical team early, and parents/caregivers and family decision-makers as appropriate.	Follow up children who have not started, have interrupted or have left treatment - whether or not the family has informed the team.
SUSPECTED ABUSE Protection of Children from Sexual Offences (POCSO) Act	Any disclosure by the child, or concerns raised through observation or by others.	Ensure the child's immediate safety. Do not investigate or repeatedly question the child. Document any disclosure verbatim, in the child's own words where possible.	Escalate through the safeguarding pathway; report to Child Protection / CHILDLINE 1098.
SUICIDE RISK ACT FAST	Ask directly about suicidal thoughts, intent, plan, access to means, and recent suicidal behaviour or attempts.	Ensure immediate safety: do not leave the child alone; restrict access to harmful means. Put a safety plan and appropriate supervision in place while awaiting assessment.	Escalate immediately: alert the treating team and arrange an urgent psychiatric assessment.
SELF-HARM ACT FAST	Any self-harming behaviour or disclosure; ask about its nature, frequency and intent.	Ensure immediate safety and attend to any injury. Individualise management to the behaviour, developmental context, underlying factors and level of risk.	Prompt assessment by a trained mental health professional of the nature, function, severity and immediate risk; refer onward if the expertise is not available locally.
HIGHLY DISTRESSED CAREGIVER	Caregiver burden, depression, anxiety and significant functional impairment.	Mild: provide information, emotional support and brief coping/grounding strategies.	Moderate to severe: refer to the psycho-oncology / mental health team for assessment and intervention.
NUTRITIONAL RISK Cancer-related feeding / eating challenges	Food aversions, anxiety and fear related to food, anticipatory nausea and vomiting, treatment-related food difficulties.	MDT assessment; psychological interventions where feeding and eating challenges have a psychosocial component.	Moderate: dietitian referral and individualised plan. High: urgent MDT review - oral/enteral/parenteral support, with psychosocial interventions as needed.

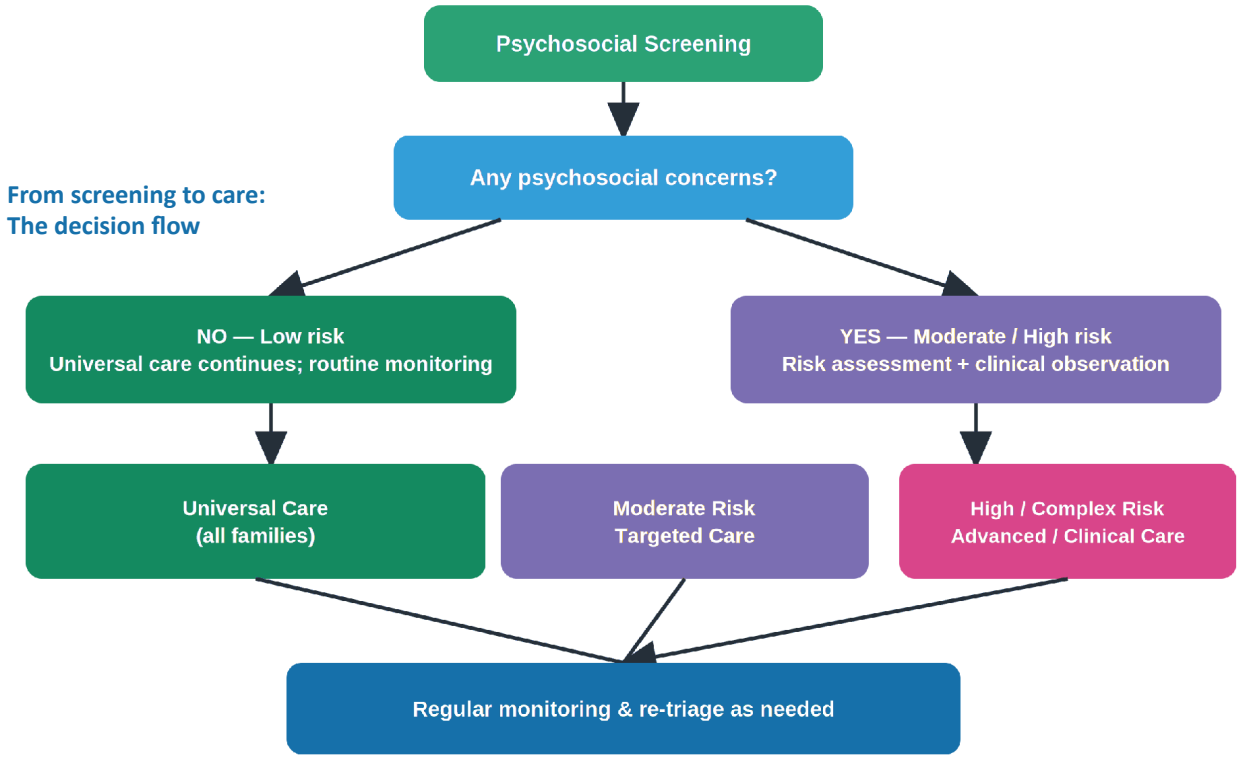
1.2 Triage - Matching Care to Need

A structured, three-tiered stepped-care model in which tiers reflect the level of psychosocial need rather than fixed interventions. CAYA and families may move between tiers as needs change across the illness trajectory.



Movement between tiers is fluid — needs may change across the illness trajectory

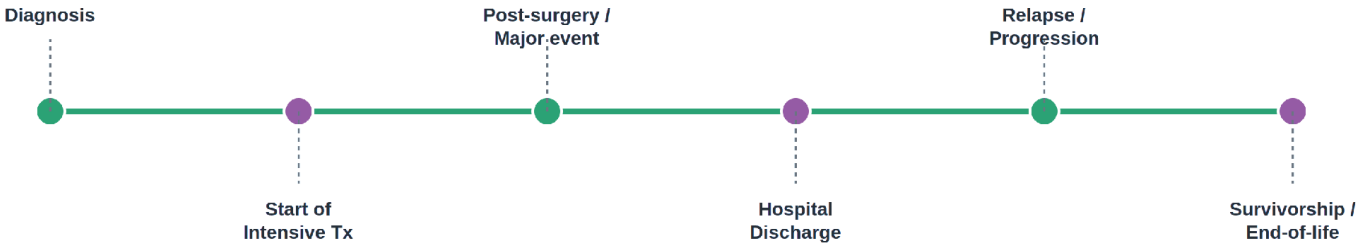
The Three-Tiered Psychosocial Triage Framework Based on PPPHM Model by Anne Kazak, 2006



Evaluation & Referral Process (simplified)

When to Re-Triage: Key Checkpoints

Psychosocial needs evolve across the illness trajectory. Reassess at key medical and developmental milestones and whenever new or worsening.



Plus: developmental milestones, family request, or provider concern at any point

1.3 Psychosocial Referral

WHEN TO REFER (BEYOND UNIVERSAL CARE)

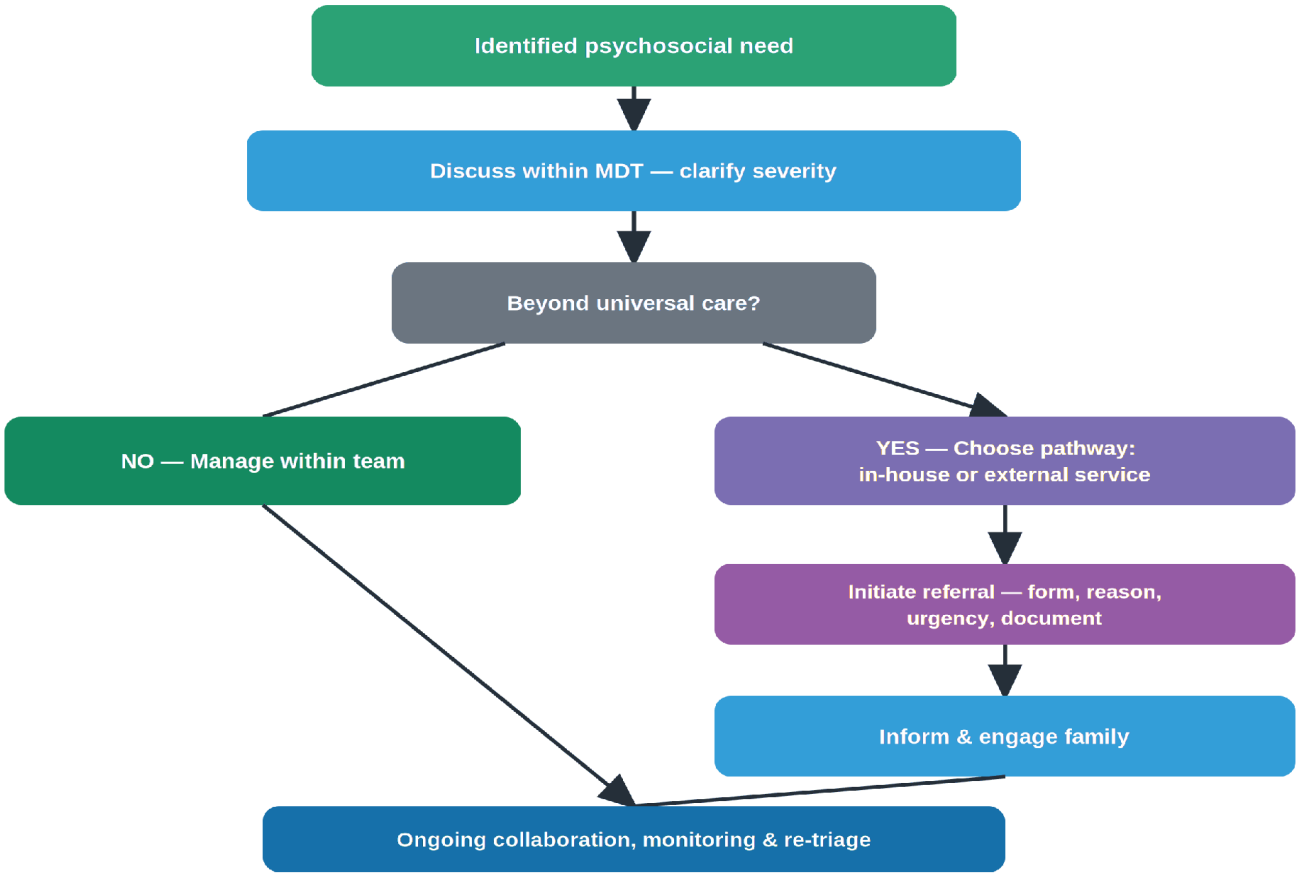
- Persistent psychological distress or functional impairment.
- Suspected or emerging mental health disorder, including depression, Post-Traumatic Stress (PTS), or suicidality.
- Concerns regarding trauma, abuse, neglect, or family abuse/violence-related concerns.
- Psychosocial needs that exceed the expertise or resources available within the treating team.

REFER TO - IN-HOUSE

- Clinical psychologists
- Psychiatrists
- Child life specialists
- Psycho-oncologists / Pediatric psycho-oncologists

REFER TO - EXTERNAL

Community mental health services
Child protection/family welfare services
School counsellors / Educational psychologists
Tele Mental Health Assistance and Networking Across States (Tele-MANAS),
Non-Governmental Organisations (NGOs) / civil society organisations



Psychosocial Referral Pathway (simplified)

10 Key Action Points

1. Implement universal psychosocial screening for all CAYA and families at defined clinical and developmental milestones.
2. Use the structured 3-tier triage model to match intervention intensity to need, with flexible movement across tiers as needs change.
3. Link screening to action - triage, intervention, referral, documentation and reassessment - within routine MDT workflows.
4. Establish clear in-house and external referral pathways to facilitate timely access to specialised care.
5. Reassess psychosocial needs at key medical, developmental and treatment-related checkpoints across the illness trajectory.
6. Prioritise assessment of suicide risk, self-harm, suspected abuse, treatment non-adherence/abandonment, and nutrition, with clear escalation and follow-up pathways.
7. Engage CAYA and families in care planning, referral decisions and shared decision-making, as appropriate to age, development and clinical context.
8. Strengthen documentation and communication across the multidisciplinary care team to support continuity of care.
9. Build MDT-wide capacity to identify psychosocial concerns and activate appropriate referral pathways.
10. Adapt tools and approaches to local language, culture and available resources.

This preview summarises Domain 1 only. The full Indian Guidelines for Psychosocial Care in Pediatric Oncology include the complete screening-tool tables; detailed stepwise management flowcharts for suicide risk, self-harm, treatment abandonment, and nutrition risk; workforce & training guidance; and the appendices-including a clinical interview guide and developmental screening checklist. For access to the complete guideline document, please contact the guideline working group or corresponding author (daruvala91@gmail.com).

Domain 2

Interventions

Interventions follow the same tiered Pediatric Psychosocial Preventative Health Model (PPPHM) used for evaluation and triage:

EVALUATION
For all Children, Adolescents and Young Adults (CAYA) & families: prevention, psychoeducation, anticipatory guidance, and basic emotional support.

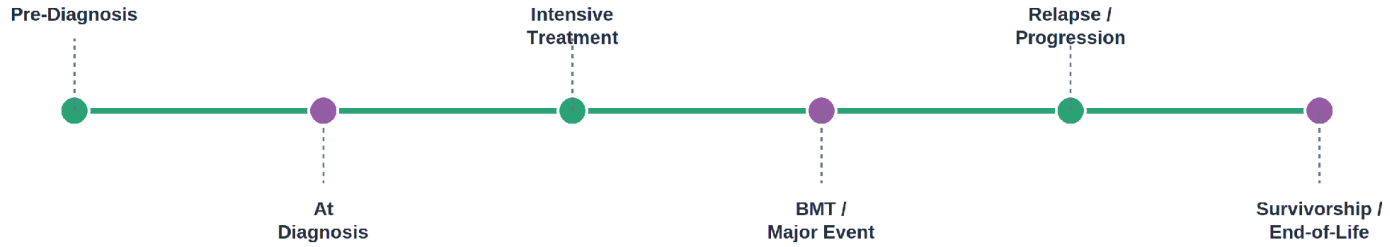
TARGETED ◆
For CAYA and families with identified psychosocial needs or moderate distress: structured, focused interventions addressing specific concerns.

ADVANCED / CLINICAL ◇
For complex, persistent or severe psychosocial needs: specialised psychological and/or psychiatric assessment and intervention.

At a glance:

1. "Intervention" refers to structured action by a trained professional to reduce distress, strengthen coping and resilience, and improve quality of life for the CAYA and the family as a unit.
2. Interventions should be proactive, not solely reactive and integrated into routine Multidisciplinary Team (MDT) care and initiated at defined clinical and developmental checkpoints.
3. Universal support remains available for every CAYA and family throughout the illness trajectory; targeted and advanced/clinical interventions are intensified as needs are identified.
4. Movement between tiers is fluid and should be guided by ongoing assessment, response to intervention, and changes in psychosocial need.

When to intervene - key checkpoints



Plus: post-treatment follow-up and at family request or provider concern, at any point

2.1 Universal Interventions: For All CAYA & Families

Foundation of care. Goals: prevent distress, promote resilience, and strengthen coping.

1. Psychoeducation: provide age- and developmentally appropriate, culturally sensitive information about diagnosis, treatment, and expected side effects, and available support.
2. Emotional normalisation and validation: acknowledge and validate emotions such as fear, sadness, anger, and uncertainty; maintain routines and meaningful activities where possible.
3. Supportive communication: use empathic, developmentally appropriate communication approaches, including frameworks such as NURSE (Name, Understand, Respect, Support, Explore).
4. Family meetings: tailor communication and shared decision-making to family needs, dynamics, and developmental considerations; family as the unit of care.
5. Peer & community support: facilitate access to peer groups, appropriate online communities, and community-based activities to reduce isolation and strengthen connection and resilience.

2.2 Targeted Interventions: For CAYA & Families with Identified Psychosocial Needs ◆

Focused interventions for specific psychosocial concerns, moderate distress, or identified risk.

Delivered by trained psychosocial professionals for CAYA and families with identified psychosocial needs or moderate distress (see Domain 1 - Evaluation, Triage & Referral).

1. Crisis counselling - provide brief, focused support during periods of increased stress such as relapse, intensive treatment, procedures, or other significant transitions.
2. Psychological interventions for CAYA - use developmentally appropriate approaches, such as play-based interventions, Cognitive
3. Behavioural Therapy (CBT), and expressive art or creative therapies, to address anxiety, depression, behavioural concerns and coping difficulties.
4. Parental support - provide individual or group counselling, psychoeducation, and training to strengthen coping skills, stress management techniques and emotion regulation skills.
5. Sibling support - provide structured individual or group interventions addressing grief, uncertainty, emotional distress, changes in family.

Quick action - Brief targeted support

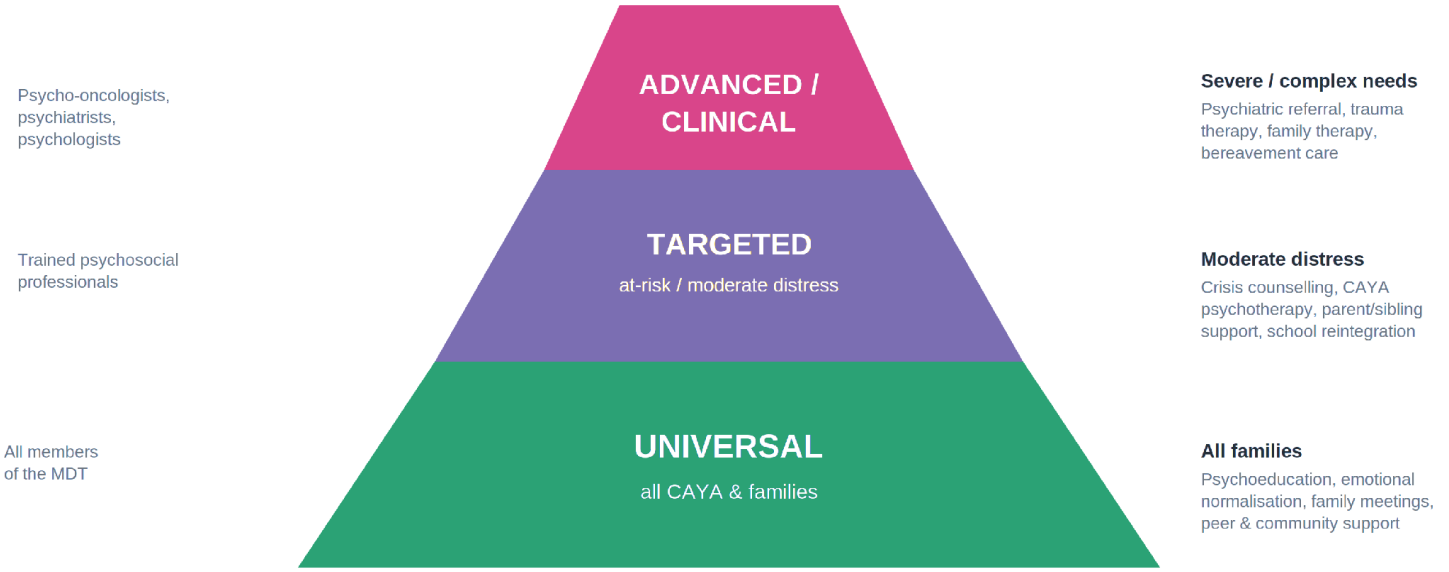
Acknowledge and normalise emotions · Identify immediate triggers and concerns · Teach one simple coping strategy (e.g., breathing, grounding, distraction) · Encourage caregiver participation · Refer for specialist assessment when distress persists, worsens, or impairs functioning.

2.3 Advanced / Clinical Interventions - for Severe or Complex Needs ◆

Specialist input required from appropriately qualified mental health or psychosocial professionals, such as psycho-oncologists, clinical psychologists, or psychiatrists.

1. Psychiatric referral & care: assessment and management of clinical depression, anxiety disorders, trauma-related disorders, suicidality, or other significant mental health concerns.
2. Trauma-informed psychological therapy: evidence-based approaches such as trauma-focused CBT (TF-CBT) or Eye Movement Desensitisation and Reprocessing (EMDR), where clinically indicated, for CAYA experiencing significant trauma-related symptoms.
3. Family therapy: addressing significant relational difficulties, caregiving stress, communication barriers affecting the CAYA or family.
4. Bereavement care: anticipatory grief support in palliative care; and structured grief counselling following the death of the child or family member, with specialist intervention when complicated or persistent grief is suspected.
5. Multidisciplinary case conferencing: Coordinated review of complex cases involving oncology, psychosocial, mental health, palliative care, and relevant community or external services.

The tiered model at a glance



Universal support continues for all families; targeted / advanced care is added as needs are identified

Quick action - Brief targeted support

Provide universal support to all CAYA and families · Identify psychosocial needs, risk and distress · Offer targeted interventions when indicated · Refer for advanced/clinical care for severe or complex needs · Continue universal support throughout the cancer trajectory.

2.4 Interventions by Common Concern: Quick ReferenceV

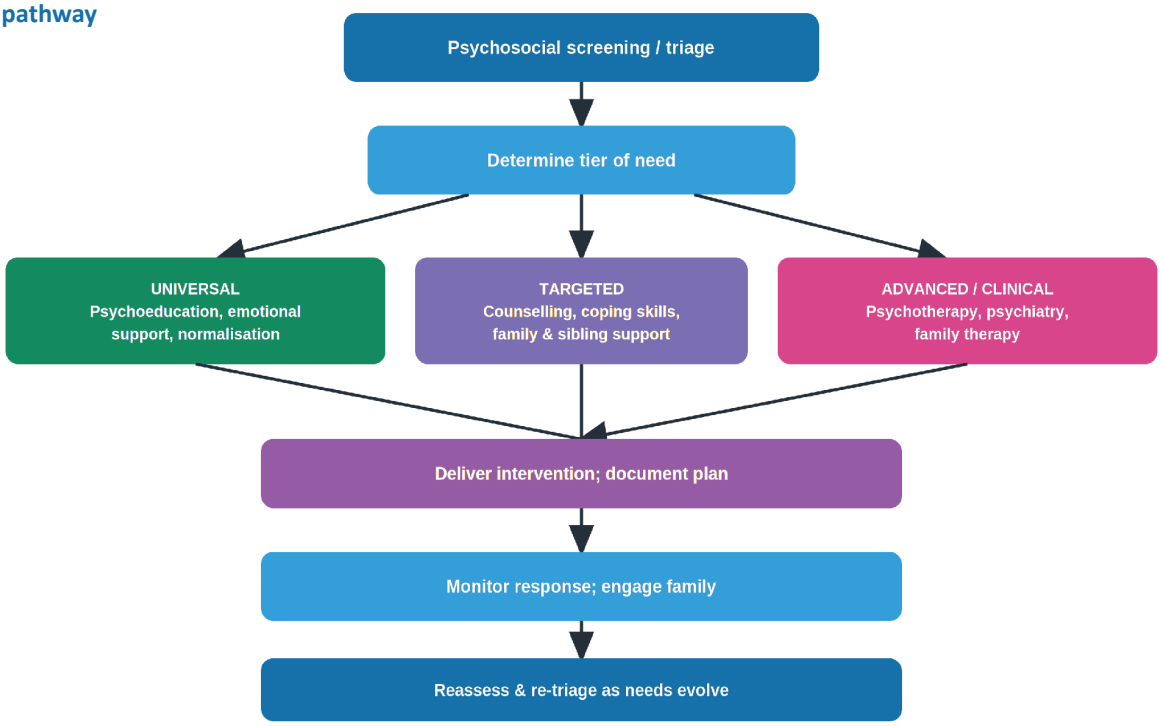
A representative selection of interventions is shown below.

[The full guideline maps 12 interventions across 9 psychological concerns, with each intervention linked to the appropriate level of care: Universal, Targeted, or Clinical, is available in the main document.]

Concern	Example intervention	Typical level
Anxiety	Psychoeducation about illness & treatment; relaxation & breathing techniques	Universal
Depression/mood difficulties	Cognitive Behavioural Therapy (CBT)	◆ Targeted
Adjustment difficulties	Expressive arts (art, music, storytelling); parent psychoeducation & coaching	Universal / Targeted
Behavioural concerns	Behavioural interventions (routines, reinforcement)	◆ Targeted
Sleep difficulties	Sleep hygiene education & behavioural sleep strategies	◆ Targeted
Separation anxiety	Therapeutic/medical play	Universal
Self-harm risk	Specialist mental health assessment and intervention	◆ Advanced/Clinical
Developmental/cognitive late effects	Cognitive/neuropsychological assessment and targeted rehabilitation	◆ Advanced/Clinical

Note: psychological and family-based interventions remain central to care. Medication may be considered only when significant psychiatric symptoms persist or a diagnosable disorder is present, and should be prescribed and monitored by a psychiatrist.

Intervention pathway



From screening to provision of intervention, monitoring and re-triage

Implementation: what makes interventions work

ADAPTATION & FLEXIBILITY

- Tailor interventions to culture, language, developmental needs, and delivery format
- Provide language or sign-language interpretation where needed and basic emotional support

STAKEHOLDER ENGAGEMENT & TRAINING

- Involve CAYA, families & clinicians in intervention design and implementation
- Provide ongoing training and supervision for non-specialist providers

FEASIBILITY & ACCESSIBILITY

- Use virtual or hybrid models where appropriate to widen access
- Consider digital literacy, privacy, connectivity and scheduling constraints

FIDELITY & QUALITY ASSURANCE

- Use manuals, monitoring tools, and regular evaluation
- Use continuous feedback to refine and improve care delivery

ADAPTATION & FLEXIBILITY

- Tailor interventions to culture, language, developmental needs, and delivery format
- Provide language or sign-language interpretation where needed and basic emotional support.

10 Key Action Points

1. Integrate psychosocial interventions as a core component of care, not an optional add-on.
2. Adopt a tiered model – Universal, Targeted, and Advanced / Clinical- aligned with level of need or risk, development, and illness trajectory.
3. Provide universal interventions to all CAYA and families including psychoeducation, emotional support, and normalisation.
4. Provide targeted interventions for moderate distress or identified psychosocial risk, including caregiver and sibling support.
5. Embed interventions within MDT care, coordinating oncology, psychosocial, and allied services.
6. Initiate interventions proactively at key clinical checkpoints, not only in response to or when there is a crisis.
7. Address the needs of the whole family unit, including parents, siblings, and caregivers.
8. Use developmentally appropriate, culturally sensitive approaches tailored to the individual and context.
9. Prioritise evidence-based psychological and family-based interventions; consider medication only when clinically indicated and under psychiatric supervision.
10. Strengthen training, supervision, stakeholder engagement, and quality monitoring to support effective & sustainable implementation.

This preview summarises Domain 2 only. The full Indian Guidelines for Psychosocial Care in Pediatric Oncology map interventions across psychological concerns to the appropriate level of care, with detailed intervention protocols and implementation guidance. The complete guideline document is available on request from the guideline working group / corresponding author (daruvala91@gmail.com).

Domain 3

Workforce and Training

This domain addresses two linked components of service delivery:

WORKFORCE
The composition, roles, competencies, and infrastructure needed to establish and sustain a pediatric psycho-oncology service.

TRAINING
A tiered competency framework to build psychosocial care skills across healthcare professionals at different levels of responsibility.

At a glance:

1. Psychosocial care requires a trained workforce and clearly defined Multidisciplinary Team (MDT) roles to prevent fragmented or inconsistent care.
2. Training follows the same tiered model as care: Universal (all relevant staff) → Targeted (psychosocial professionals) → Advanced/Clinical (specialists).
3. Where specialist workforce is limited, task-sharing, tele-psycho-oncology, and hub-and-spoke supervision can extend access and specialist support.

3.1 Workforce - Building the Service

Quick action - Brief targeted support

Provide universal support to all CAYA and families · Identify psychosocial needs, risk and distress · Offer targeted interventions when indicated · Refer for advanced/clinical care for severe or complex needs · Continue universal support throughout the cancer trajectory.

Core MDT roles

Role	Key responsibility	Tier
Lead Psycho-Oncologist / Psychologist	Service design, clinical leadership, supervision, policy	Universal + Targeted + Advanced/Clinical
Psycho-oncologists / Psychologists / Counsellors	Individual & group interventions, family counselling	Targeted + Advanced/Clinical
Medical Social Workers	Psychosocial assessment, practical and financial counselling, community linkage	Universal + Targeted
Child Life Specialists / Play Therapists	Therapeutic play, procedural preparation, coping support	Universal + Targeted
Pediatric Psychiatrist	Assessment and management of complex psychiatric conditions and pharmacological care when indicated	Advanced/Clinical
Patient Navigators / Care Coordinators	Care coordination, system navigation, and reduction of logistical barriers	Universal + Targeted

PHASE 1 - PLANNING

- Convene stakeholder meetings to define goals, roles, and scope.
- Allocate appropriate space, staffing, and essential resources.

PHASE 2 - PILOT

Start with a limited team & priority population.

Monitor workflow, feasibility, uptake and intervention delivery.

PHASE 3 - EXPANSION

Scale up staffing & services.

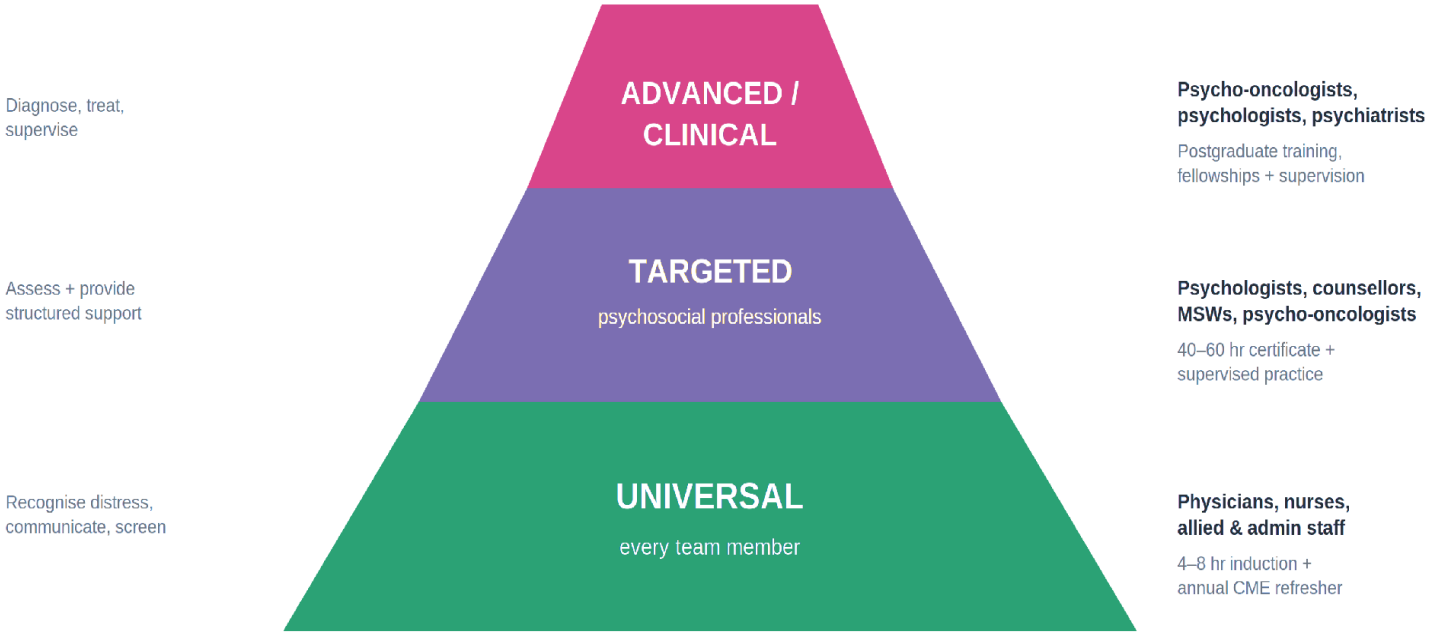
Gradually add survivorship, bereavement, and outreach, and other services as capacity develops.

Quick action - Resource-limited settings: where to prioritise

Prioritise: screening & triage capability · one designated psychosocial lead · clear referral pathways for high-risk cases · basic parent and caregiver guidance. Avoid: ad hoc counselling without assessment or triage, and screening without a linked referral and management pathway. This carries harm risk. Screening should be implemented only where appropriate follow-up and escalation mechanisms are available.

3.2 Training - Building Competency

A tiered competency framework: all healthcare professionals need basic psychosocial skills; identified psychosocial needs require targeted skills; complex or high-risk concerns require specialist expertise.



All families receive Universal care; escalation to higher tiers is need-based

Mandatory across all levels: case-based learning and supervised clinical exposure.

Non-negotiable competencies (Universal level)

1. Recognise signs of distress in Children, Adolescents and Young Adults (CAYA), parent, and sibling.
2. Use basic empathic communication skills, such as NURSE responses (Name, Understand, Respect, Support, Explore).
3. Understand and appropriately use basic psychosocial screening tools (e.g., Distress Thermometer, Psychosocial Assessment Tool (PAT)), whereapplicable.
4. Recognise when to refer and know the appropriate referral pathway.

3.3 Quality, Scale-Up & Adaptation - Quick Reference

QUALITY INDICATORS TO TRACK

- CAYA/families screened; appropriately referred following screening
- Time from identification of need to psychosocial intervention
- Treatment interruptions or dropout associated with unresolved psychosocial barriers
- Family experience and satisfaction with psychosocial care

TRAINING SYSTEM RED FLAGS

- Psychosocial care provided only on requestrather than routine care.
- No routine psychosocial screening; referrals occur only during crisis episodes
- No defined supervision, competency assessment or documentation system

TASK-SHARING (INDIA-SPECIFIC)

- Nurses: basic screening and initial emotional support
- MSWs: family support, financial assistance and system navigation
- Regular MDT/case review, virtual review acceptable where in-person specialist support is limited

SCALING NATIONALLY

- Integrate foundational psychosocial training into continuing medical education (CME) programmes
- Develop national certificate programs; Extension for Community Healthcare Outcomes (ECHO)-type tele-mentoring
- Use standardised, International Society of Paediatric Oncology (SIOP) / International Psycho-Oncology Society (IPOS)-aligned resources

10 Key Action Points

1. Establish pediatric psycho-oncology services in phases - planning, pilot, expansion - with clear goals, defined roles and MDT integration.
2. Develop a multidisciplinary workforce with psycho-oncologists, clinical psychologists, social workers, child life/play specialists, school liaison and spiritual care where available, and access to psychiatric expertise.
3. Ensure appropriate infrastructure, including child- and family-friendly consultation and therapeutic spaces.
4. Establish clear policies for referral, documentation, confidentiality, safeguarding and crisis management.
5. Adopt a tiered competency framework - Universal, Targeted and Advanced/Clinical - for healthcare professionals.
6. Ensure all relevant healthcare professionals receive universal/foundational training in communication, distress recognition and referral.
7. Provide structured targeted training with supervised clinical practice for psychosocial providers.
8. Develop advanced training pathways, including specialist programmes and fellowships, for complex psychosocial and psychiatric needs.
9. Use task-sharing, tele-psycho-oncology and hub-and-spoke supervision to extend specialist support where workforce capacity is limited.
10. Establish monitoring, evaluation and feedback systems for continuous quality improvement and sustainable scale-up.

This preview summarises Domain 3 only. The full Indian Guidelines for Psychosocial Care in Pediatric Oncology include complete role and training-module tables, guidance on cultural competence and technology-enabled care, and the full implementation and scale-up strategy. To request the full guideline document, please contact the guideline working group / the corresponding author (daruvala91@gmail.com).

Domain 4

Support for Siblings and Caregivers

This domain places the family at the centre of care - three connected groups:

CHILD / CAYA	CAREGIVERS	SIBLINGS
At the centre of care; their wellbeing is closelylinked to how the family copes.	Emotional distress, decision-making burden, caregiving fatigue, and financial and practical strain.	Fear, guilt, feeling overlooked, behavioural change and school difficulties.

Family = unit of care. Supporting caregivers and siblings supports the child - and the whole family's adjustment.

At a glance:

1. Caregivers of Children, Adolescents and Young Adults (CAYA) with cancer may experience significant psychological distress; routine attention to caregiver wellbeing is an integral part of comprehensive care.
2. Siblings may experience fear, guilt, reduced parental attention and behavioural change; their needs can be overlooked unless they are deliberately considered and assessed.
3. Caregiver and sibling support follows the same tiered model: Universal support for all families → Targeted support for identified/moderate distress or psychosocial risk → Advanced/Clinical specialist care for severe persistent, or complex needs.

Quick action - Family-centred care checklist at every major review

How is the caregiver coping? How are the siblings coping? Has financial stress changed? Does the family understand the treatment plan? Are additional psychosocial supports required? The family — not only the patient — is the unit of care.

4.1 Caregivers - Recognising & Responding to Distress

Common domains of Caregiver Burden

1. Emotional distress - anxiety, depressive symptoms, fear of relapse, and uncertainty about prognosis.
2. Decision-making burden - navigating complex medical choices, often involving shared or family-based decision-making.
3. Caregiving fatigue & burnout - physical and emotional exhaustion associated with sustained caregiving demands.
4. Financial & practical strain - treatment-related costs, travel, accommodation, employment disruption, and lost income.
5. Marital/family strain & role disruption - changes in couple and family dynamics, employment, routine disruption and caregiving roles.

Quick action - Caregiver distress identified

Provide universal support to all CAYA and families · Identify psychosocial needs, risk and distress · Offer targeted interventions when indicated · Refer for advanced/clinical care for severe or complex needs · Continue universal support throughout the cancer trajectory.

Watch for High-Risk Caregivers

1. Previous mental health concerns.
2. Single or unsupported caregiver.
3. Financial hardship.
4. Limited social support.
5. Relapse or poor prognosis.
6. Significant caregiver exhaustion/burnout.

Caregivers with increased psychosocial risk benefit from early assessment and appropriate intervention - not only crisis referral.

Interventions for caregivers - tiered

Level	Example interventions	Providers
Universal (all caregivers)	Psychoeducation, treatment-phase preparation, coping strategies, caregiving guidance	Oncology team; trained psychosocial staff
◆ Targeted - Identified / moderate distress or psychosocial risk	Individual counselling, parent/caregiver support groups, stress management, parenting guidance	Psychologists, Medical Social Workers (MSWs)
◆ Advanced/Clinical- severe, persistent, or complex needs or distress	Individual psychological intervention, psychiatric assessment, crisis intervention, family therapy	Psychiatrists, psycho-oncologists, Clinical psychologists

4.2 Siblings - Recognising & Responding to Distress

Common experiences reported among siblings

1. Fear, confusion, and uncertainty about the illness; feelings of guilt or self-blame about being well.
2. Feeling overlooked or less attended to as family attention focuses on the child with cancer.
3. Emotional and Behavioural change - irritability, withdrawal, acting out, or regression.
4. School-related difficulties - concentration, attendance, participation, or academic performance.
5. Increased responsibilities at home that may exceed age or developmentally appropriate expectations.

Quick action - Caregiver distress identified

Provide universal support to all CAYA and families · Identify psychosocial needs, risk and distress · Offer targeted interventions when indicated · Refer for advanced/clinical care for severe or complex needs · Continue universal support throughout the cancer trajectory.

Interventions for caregivers - tiered

Level	Example interventions	Providers
Universal (all siblings)	Age-appropriate information, inclusion in discussions, hospital familiarisation, Support for continuity of school and daily routines	Parents/caregivers, oncology team
◆ Targeted Identified distress or psychosocial risk	Sibling support groups, psychoeducation, school-based support, play and expressive arts activities	Psycho-oncologists, Clinical Psychologists, child life specialists
◆ Advanced/Clinical- severe, persistent, or complex distress / needs	Individual psychological intervention, behavioural intervention, specialist mental health care	Psycho-oncologists, Clinical psychologists, psychiatrists

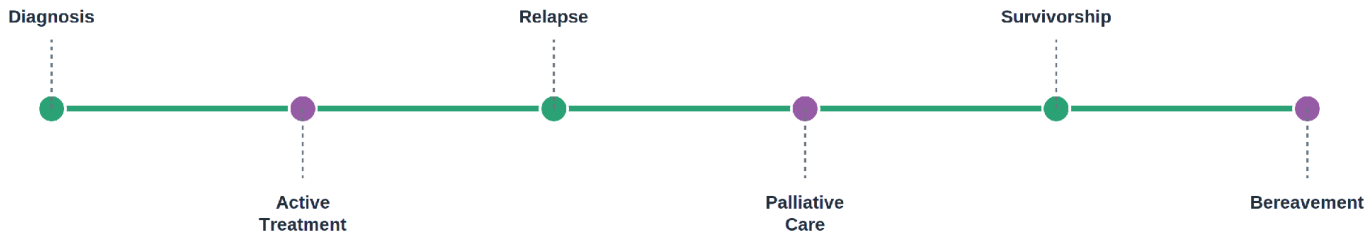
Refer when sibling distress persists

Withdrawal · School difficulties · Persistent sadness or anxiety · Aggression or regression · Guilt or self-blame · Recurrent somatic complaints. Persistent or worsening distress, particularly when it interferes with daily functioning, warrants further assessment and appropriate psychosocial or mental health support.

4.3 Flexible Delivery & Escalation

How is the caregiver coping? How are the siblings coping? Has financial stress changed? Does the family understand the treatment plan? Are additional psychosocial supports needed? The family - not only the patient - is the unit of care.

Interventions for caregivers - tiered



Caregiver and sibling needs shift at each stage — support should be offered proactively, not only on request

RESOURCE-LIMITED SETTINGS	TELE-SUPPORT	COMMUNITY & NON-GOVERNMENTAL ORGANISATION (NGO) PARTNERS
Integrate basic support into routine care. Train physicians, nurses, MSWs to recognise distress and initiate appropriate support and referral.	Use phone, video, messaging to extend psychosocial support to families who have difficulty accessing in-person services. Useful for follow-up counselling, continuity of care and peer support.	Engage school counsellors, community health workers and relevant NGOs to extend psychosocial support. Community and NGOs may provide counselling, practical/financial and peer support, with referral to specialist services when required.

Refer when sibling distress persists

Severe caregiver depression or anxiety | Suicidal thoughts or behaviour | Family violence or safeguarding concerns | Persistent sibling distress | Significant family dysfunction | Inability to provide safe or adequate caregiving

Escalate early - complex family needs may require multidisciplinary care.

10 Key Action Points

1. Recognise caregivers and siblings as integral to family-centred care, and integrate their support within MDT care.
2. Assess caregiver distress and sibling wellbeing routinely using observation, conversation and appropriate screening tools.
3. Identify families at higher psychosocial risk early - limited support, financial strain, high caregiving burden - and link them to financial and practical support.
4. Provide universal psychosocial support to all caregivers and siblings as a baseline.
5. Offer targeted interventions - counselling, support groups, parenting guidance and school-based support - and ensure access to specialised mental health care for significant distress.
6. Support caregivers in decision-making and communication through clear, shared information.
7. Enable a parent or caregiver to stay with the child during hospitalisation, and promote caregiver self-care, help-seeking and social support networks.
8. Maintain the sibling–patient relationship through connection, age-appropriate involvement, normal roles and open communication.
9. Adapt support and care to cultural, socioeconomic and contextual factors relevant to Indian families.
10. Use flexible delivery - task-sharing, tele-support, and NGO, community and parent-group collaboration - to expand access.

This preview summarises Domain 4 only. The full Indian Guidelines for Psychosocial Care in Pediatric Oncology include comprehensive assessment tables, validated screening tools for caregivers and siblings, and detailed cultural and contextual guidance. The complete guideline document is available on request from the guideline working group / corresponding author (daruvala91@gmail.com).

Domain 5

End of Treatment, Survivorship and Reintegration

This domain covers three connected phases of care:

END OF TREATMENT	SURVIVORSHIP	REINTEGRATION
Emotional adjustment, transition preparation, introduction of the Survivorship Passport.	Late-effect monitoring, resilience, identity, Survivorship Passport in use.	School, social, family and community participation.

Phases overlap and are continuous - reintegration planning begins at the end of treatment. The same tiered model (Universal → Targeted → Clinical) applies at every

At a glance:

1. End of treatment (EoT) marks the beginning of survivorship, not the end of care - reintegration planning starts here.
2. The same tiered model (Universal → Targeted → Clinical) is used across each phase, with care adjusted as needs evolve.
3. The Survivorship Passport provides continuity across EoT, survivorship, reintegration, and eventual transition to adult care.

5.1 End of Treatment (EoT)

Goals of care at EoT

1. Support emotional adjustment to treatment completion - relief, anxiety, and uncertainty may coexist.
2. Prepare the family for survivorship - follow-up schedule, potential late effects and changed routine.
3. Identify psychosocial and functional risks and needs early through structured evaluation.
4. Begin reintegration planning and introduce the Survivorship Passport (described in section 5.2).

Quick action - The EoT visit

Acknowledge mixed emotions (relief + anxiety) | Explain the transition to survivorship | Review the follow-up schedule · Introduce the Survivorship Passport | Identify immediate psychosocial concerns.

End of treatment is the beginning of survivorship - not the end of care.

Interventions at EoT - tiered

Level	Example interventions	Providers
Universal (all)	Psychoeducation on post-treatment expectations; normalising mixed emotions; structured EoT counselling; Introduction to the Survivorship Passport	Oncology team
◆ Targeted (identified need / moderate)	Coping with fear of relapse; school re-entry preparation; parent guidance on overprotection; Support for adjustment to changed routines	Psycho-oncology professionals
◆ Clinically significant or complex need	Evidence-based psychotherapy (e.g., Cognitive Behavioural Therapy (CBT), trauma-informed approaches); psychiatric assessment/referral; family therapy	Mental health specialists trained in oncology

5.2 Survivorship

Three overlapping phases: early (0–6 months), extended (6 months–5 years), and long-term (beyond 5 years) survivorship.

Domains monitored across survivorship

1. Emotional wellbeing, neurocognitive function, social and educational functioning.
2. Identity and developmental progression, family functioning, physical and functional status.
3. Health behaviours and adherence to follow-up, particularly during adolescence and the transition to adult care.
4. Fertility-related concerns in adolescents and young adults, with access to fertility counselling where appropriate.

Quick action - Ask at every follow-up

How are you coping emotionally? How is school or college going? Any new fears or worries? Any physical difficulties or limitations? Do you know when your next follow-up is?

Routine conversations can identify concerns early.

Interventions in survivorship - tiered

Level	Example interventions	Providers
Universal (all)	Psychoeducation; health promotion; routine survivorship follow-ups; peer support	Oncology team
◆ Targeted (identified need / moderate)	Coping Skills Training; Social Skills Development; Academic Support; Parent Guidance	Psycho-oncology professionals
◆ Clinical (significant or complex need)	Evidence-based Psychotherapy; neuropsychological assessment and rehabilitation; psychiatric assessment and care; multidisciplinary management	Mental health specialists and relevant rehabilitation professionals with understanding of oncology

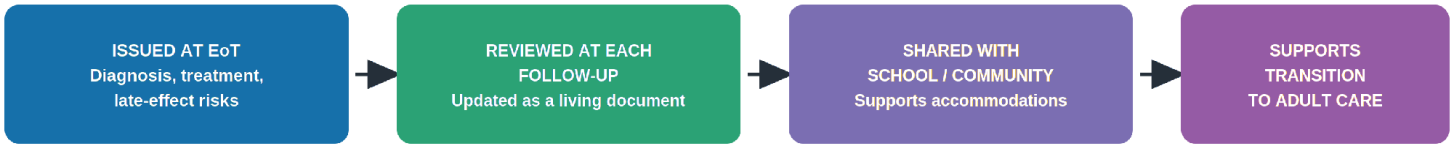
Survivorship Passport - the core continuity tool

A structured, patient-held document summarising diagnosis, treatment exposures, late-effect risks, and follow-up needs. It supports continuity of care across providers, schools, and the transition to adult care.

Quick action - Issue the Survivorship Passport

Every survivor should receive: diagnosis summary · treatment history · late-effect risks · follow-up schedule · emergency information · psychosocial recommendations.

Issue it. Explain it. Update it. Use it.



Issue it. Explain it. Update it. Use it.

5.3 Reintegration

Goals of reintegration

1. Support participation in age-appropriate roles and activities - school, peers, family, recreation.
2. Promote independence, reduce stigma, and support re-establishment of meaningful routines
3. Support continued education during treatment through hospital-based school services where available, easing later school re-entry.

Evaluation domains for reintegration

SCHOOL / EDUCATION READINESS	SOCIAL FUNCTIONING	FAMILY DYNAMICS	COMMUNITY PARTICIPATION
Attendance and academic gaps, Cognitive functioning, fatigue, confidence	Peer confidence, stigma and bullying, Social withdrawal	Overprotection, Caregiver Anxiety, Sibling Adjustment	Sports and hobbies, Community events; Physical & access barriers

Interventions for reintegration - tiered

Level	Example interventions	Providers
Universal (all)	School re-entry planning; teacher sensitisation; peer awareness; gradual reintegration plans	Oncology team, School liaison where available
◆ Targeted (identified need/moderate risk)	Social skills training; academic support/remediation; individualised reintegration plans; parent coaching	Psychosocial professionals (psycho-oncologist, Psychologist); special educator
◆ Clinical (significant or complex need/high risk)	Therapy for school refusal or persistent withdrawal; family therapy; multisystem interventions	Clinical psychologist, psychiatrist, Multidisciplinary Team (MDT)

Quick action - Reintegration challenges

IF THE CHILD IS WITHDRAWING

- Explore bullying or stigma; assess peer confidence
- Encourage gradual social activity; consider peer support
- Refer if avoidance persists- social recovery is part of cancer recovery

WHEN CAREGIVERS STRUGGLE TO LET GO

- Validate ongoing fears; encourage age-appropriate independence
- Promote normal routines; discuss realistic safety measures
- Support caregivers to protect without unnecessarily limiting development.

5.4 Monitoring at Follow-Up - Key Parameters

Ten domains are assessed at each follow-up:

1. School functioning	**6.** Physical and functional status
2. Cognitive and learning function	**7.** Community participation
3. Social functioning	**8.** Adherence and health behaviours
4. Emotional wellbeing	**9.** Use of supports
5. Family functioning	**10.** Overall adjustment

10 Key Action Points

1. Recognise EoT, survivorship and reintegration as continuous phases requiring structured psychosocial care.
2. Conduct systematic evaluation at EoT and at regular intervals across survivorship and reintegration.
3. Use the tiered model (Universal, Targeted, Clinical) for risk- and needs-based assessment and intervention at every phase.
4. Provide structured EoT support: psychoeducation, normalisation and a dedicated counselling session.
5. Initiate reintegration planning at EoT - school return, social participation, restoration of routines - supported by teacher sensitisation and peer awareness.
6. Implement longitudinal monitoring across emotional, neurocognitive, social, educational and functional domains, including mental health at every long-term follow-up visit.
7. Initiate the Survivorship Passport at EoT, update it at each follow-up, and use it across providers and settings for continuity and family empowerment.
8. Ensure access to clinical interventions for significant or complex reintegration challenges.
9. Strengthen coordination across healthcare, school and community systems.
10. Plan and support transition to adult care, fostering independence in adolescents and young adults.

This preview summarises Domain 5 only. The full Indian Guidelines for Psychosocial Care in Pediatric Oncology include comprehensive evaluation tables, referral pathway figures, the full survivorship passport template (Appendix 1), and detailed monitoring guidance. The complete guideline document is available on request from the guideline working group/corresponding author (daruvala91@gmail.com).

Domain 6

End of Life Care and Bereavement

This domain covers one continuum of support across four phases:

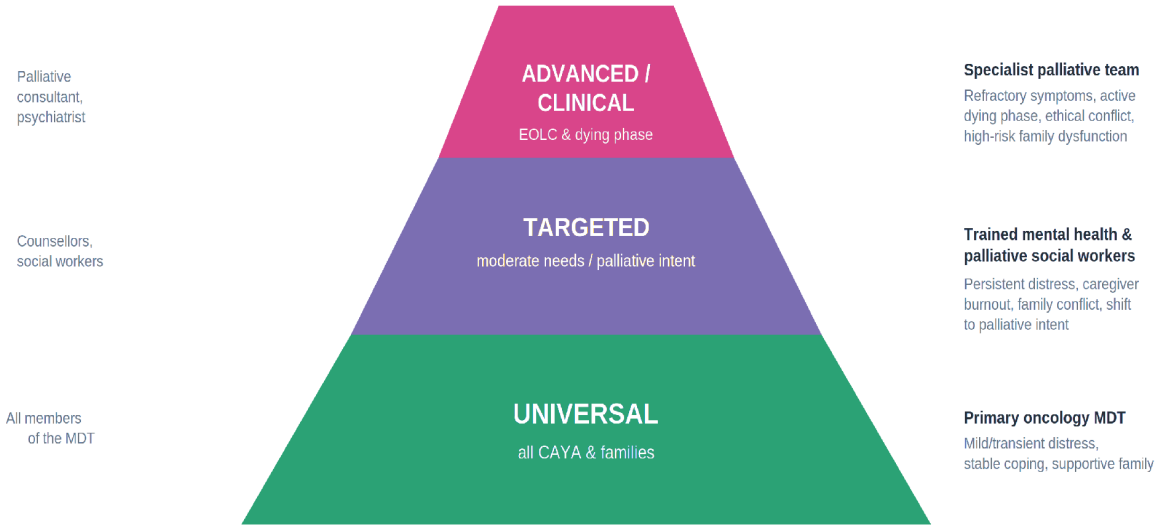
DISEASE PROGRESSION / RELAPSE	PALLIATIVE PHASE	END-OF-LIFE & TERMINAL PHASE	BEREAVEMENT
Fear, uncertainty, family destabilisation.	Existential concerns, caregiver guilt and burnout, shift in goals of care.	Anticipatory grief, spiritual needs, comfort and presence.	Grief, disorientation, role change, risk of complicated grief.

Support begins at diagnosis and continues as a single continuum - not four separate services.

At a glance:

1. "Total pain"- suffering extends beyond physical symptoms to psychological, social & spiritual distress. The family is the unit of care.
2. Palliative care is guided by need, not prognosis, and can begin early alongside disease-directed treatment.
3. The tiered model (Universal → Targeted → Advanced/Clinical) is dynamic: movement between tiers may occur repeatedly, in either direction, as needs change.

6.1 Caregivers - Recognising & Responding to Distress



Quick action - When to initiate a palliative psychosocial consult

Consider early referral when: disease progression or relapse · recurrent Intensive Care Unit (ICU) admissions · high symptom burden · significant psychosocial distress · family conflict or differing views about goals of care · uncertainty about future planning. Transition away from disease-directed treatment.

Palliative care should be guided by need - not prognosis.

Urgent / red-flag escalation triggers

1. Active suicidal ideation or imminent self-harm risk | Severe agitation, delirium, or unmanaged neuropsychiatric distress.
2. Acute family conflict or safeguarding concerns affecting care or decision-making | Rapid clinical decline accompanied by overwhelming distress.

Immediate specialist involvement is required regardless of the stage of care. Escalation and de-escalation are not linear - reassess regularly and adjust care as needs change.

6.2 Communication & Care Planning

Quick action - Caregiver distress identified

Ask what they already know | Use developmentally appropriate language | Avoid euphemisms ("sleep","going away") | Allow questions | Validate emotions | Revisit conversations over time.

Honest, developmentally appropriate communication can reduce uncertainty and support coping.

Quick action - The family/goals-of-care meeting

Confirm who should be present | Clarify the family's understanding | Explore hopes and worries | Discuss prognosis honestly and sensitively | Recognise and handle collusion | Agree on immediate goals of care | Summarise decisions and next steps | Document the discussion.

Clear, consistent communication helps prevent misunderstandings and supports shared decision-making.

Advance Care Planning (ACP) - core components

Component	What it covers	Nature
Goals of care	Priorities such as quality of life, comfort, and the balance between life-prolonging and comfort-focused care	Ongoing, revisited as needs change
Treatment preferences	Preferences regarding treatment escalation, limitation of treatment and life-support measures	Documented, dynamic
Place of care and death	Home, hospice, or hospital, based on feasibility, safety, and available support	Preference-led; may change
Life-threatening events	Resuscitation and emergency care planning broader than a Do Not Attempt Resuscitation (DNAR) order	Shared planning with the Multidisciplinary Team (MDT) and family.

Parallel planning: prepare simultaneous plans for stabilisation and deterioration - this reduces crisis-driven decisions and supports hope alongside preparedness.

6.3 The Dying Phase

Recognising The Terminal/Dying Phase (Hours To Days)

1. Reduced oral intake; altered consciousness including increasing sleepiness, confusion, or reduced responsiveness.
2. Increasing fatigue and weakness; changes in breathing and circulation.

Core Elements Of A Relational "Good Death"

1. Total pain and symptom relief - relieve physical and psychological distress; discontinue or avoid non-beneficial interventions where appropriate.
2. Relational security - support continuous caregiver presence where desired; facilitate sibling involvement when appropriate; provide reassurance and emotional connection.
3. Cultural and spiritual preferences-facilitate religious, spiritual and cultural practices, preferred rituals and the family's preferred place of care where feasible.

Avoid rigid benchmarks - a "good death" is not a fixed script. The dying process may be unpredictable; support families without implying that they have failed if the course differs from expectations.

Quick action - Preparing for end of life

Ensure the family understands:
Expected physical changes | symptom management plan | Who to contact, day and night | Preferred place of care | Cultural and spiritual wishes | Memory-making opportunities | Who wishes to be present.
Good preparation can reduce uncertainty, support dignity and help families feel more prepared.

6.4 Grief & Bereavement

Anticipatory Grief - Before Death

1. Expect varied emotions - fluctuating hope and despair, guilt, anger, and helplessness may occur and do not necessarily indicate poor coping.
2. Approach: normalise and validate emotions, encourage honest, developmentally appropriate conversations, involve siblings appropriately, support legacy-building and make space for spiritual and existential concerns.

IMMEDIATELY AFTER DEATH - FIRST PRIORITIES

- Confirm death compassionately; give and allow the family time and privacy with the child sensitively
- Facilitate cultural and religious rituals; explain practical next steps clearly and sensitively
- Support siblings and other family members; arrange bereavement follow-up

BEREAVEMENT FOLLOW-UP DOES NOT END CARE AT DEATH

- Make contact within 1–4 weeks and assess grief, coping and immediate support needs
- Identify risk factors for prolonged or complicated grief and support siblings
- Offer bereavement counselling and connect with appropriate community or peer supports

Quick action - Staff wellbeing after every pediatric death

Conduct a team reflection or debrief | Reflect on what went well | Identify learning points | Check staff wellbeing | Offer supervision or additional support when needed · Document service improvements.

Supporting the team helps sustain compassionate care.

10 Key Action Points

1. Integrate palliative psychosocial care early, alongside disease-directed treatment - not only at end of life.
2. Recognise the family as the unit of care and address total pain - physical, emotional, psychological, social and spiritual distress.
3. Use the tiered model with dynamic triage; escalate or de-escalate according to need, not prognosis.
4. Ensure developmentally appropriate, honest and culturally sensitive communication throughout the illness trajectory.
5. Facilitate family meetings and shared decision-making; respond sensitively to requests to withhold or limit information.
6. Implement Advance Care Planning as a dynamic, ongoing process, using parallel planning to prepare families for multiple possible trajectories.
7. Deliver compassionate, family-centred care during the dying phase, prioritising comfort and dignity in the family's preferred setting - hospital, home or hospice.
8. Facilitate memory-making and legacy-building according to family readiness, preferences and cultural context.
9. Provide immediate post-death support and ongoing bereavement care, including support for siblings.
10. Support healthcare provider wellbeing through reflective practice, supervision, debriefing and institutional support.

This preview summarises Domain 6 only. The full Indian Guidelines for Psychosocial Care in Pediatric Oncology include comprehensive assessment and triage tables, referral pathway figures, home-based care guidance, and cultural, ethical, and legal considerations relevant to the Indian context. The complete guideline document is available on request from the guideline working group / corresponding author (daruvala91@gmail.com).

Domain 7

Staff Support and Burnout

This domain addresses staff wellbeing at three connected levels:

INSTITUTIONAL	TEAM	INDIVIDUAL
Policy, leadership, workload.	Supervision, peer support, debriefing, culture.	Self-care, boundaries, rest, reflection.

Staff wellbeing is an institutional responsibility, not an individual burden.

At a glance:

1. Recognise occupational risks - Burnout, empathic distress (compassion fatigue), secondary traumatic stress, and moral distress may occur in pediatric oncology work and do not indicate individual weakness.
2. Make staff wellbeing an institutional responsibility - embed support within organisational policy, workflow and team culture rather than placing responsibility solely on individuals.
3. Use practical, low-resource approaches - even where formal wellness programs are not available, feasible team-based and individual strategies can support staff wellbeing.

7.1 Understanding Burnout & Related Phenomena

Burnout: a work-related syndrome characterised by emotional exhaustion, cynicism or detachment, and reduced sense of professional efficacy.

EMPATHIC DISTRESS (COMPASSION FATIGUE)	SECONDARY TRAUMATIC STRESS	MORAL DISTRESS
Emotional and physical exhaustion associated with prolonged or repeated exposure to others' suffering and caregiving demands.	Trauma-related stress responses arising from indirect exposure to another person's traumatic experiences, which may include intrusive thoughts, avoidance or hypervigilance	Distress that arises when a person recognises the ethically appropriate action but is constrained from taking it by institutional, systemic or other barriers.

Quick action - Managing moral distress

When values and care conflict: pause and discuss with the Multidisciplinary Team (MDT). Clarify clinical goals, ethical concerns, family perspectives, and relevant institutional policies. Seek guidance when uncertainty persists. Escalate unresolved dilemmas for ethics consultation where available. Moral distress is easier to address when concerns are recognised early and shared with the team.

7.2 Recognising Burnout & Risk Factors

Quick action - Watch for the warning signs

Emotional exhaustion | Cynicism or detachment | Reduced empathy | Irritability | Feeling ineffective | Frequent or increased absenteeism | Withdrawal from work or desire to leave the profession.

Early recognition creates an opportunity for timely support and intervention

Risk factors - individual, team, institutional

CLINICAL & EMOTIONAL DEMANDS	WORKLOAD & RESOURCE LIMITS	ROLE AMBIGUITY & RECOGNITION	PERSONAL FACTORS
Prolonged relationships across the illness trajectory; cumulative grief; · repeated exposure to suffering and loss	High caseloads; time pressure; limited opportunities for reflection, supervision or debriefing	Unclear roles and responsibilities; emotional labour that may be invisible or insufficiently recognised	Early-career challenges; high emotional demands; limited access to support or opportunities for recovery

7.3 Institutional Support Structures

Quick action - Leadership checklist

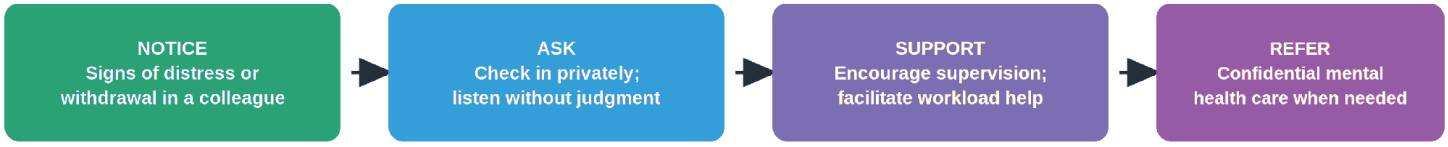
Department leads should ensure: regular supervision | Protected time for reflection and debriefing | Reasonable workloads | Access to confidential support | Ongoing training | Periodic wellbeing review.

Staff wellbeing is an institutional responsibility, not an individual burden.

Core structures

Structure	What it addresses	Format
Clinical supervision	Emotional responses, ethical dilemmas, professional boundaries, complex family dynamics	Individual or small group
Peer support and debriefing	Team responses to deaths, critical incidents, difficult ethical decisions	Structured team debrief; promptly, ideally within 24–72 hours
MDT meetings	Care coordination, share concerns, communication gaps; collaborative problem-solving	Regular and routine
Training and development	Difficult conversations, recognition of burnout and distress, coping and resilience skills · reflective practices, mindfulness	Ongoing / Continuing Professional Development (CPD)
Confidential mental health access	Voluntary, confidential support for significant distress or mental health concerns	As needed, accessible and stigma-free

Notice → Ask → Support → Refer



Supporting colleagues is everyone's responsibility

7.4 Team Culture & Self-Care

BUILDING A SUPPORTIVE TEAM CULTURE

- Hold regular MDT meetings and encourage respectful, open communication
- Recognise emotional labour and acknowledge staff contributions
- Normalise conversations about stress and wellbeing- supportive teams help protect staff wellbeing

LOW-RESOURCE WELLBEING STRATEGIES

- Use brief, regular team check-ins and informal peer support
- Rotate demanding duties where feasible and encourage annual leave and rest periods.
- Recognise staff efforts and achievements- small consistent changes can strengthen team wellbeing

Quick action - The 5-minute daily self-check

Am I emotionally exhausted? Have I felt detached from patients or families? Am I getting adequate rest and sleep? Have I connected with a colleague today? Do I need support?

Regular self-checks can help recognise early signs of strain and prompt timely support.

10 Key Action Points

1. Recognise staff wellbeing as a core component of quality care and an institutional responsibility.
2. Recognise burnout, empathic distress (compassion fatigue), secondary traumatic stress and moral distress as occupational risks in pediatric oncology care.
3. Establish work environments that promote open communication, respect and recognition of emotional labour, and reduce stigma around help-seeking.
4. Integrate staff support into routine workflows through check-ins, supervision and opportunities for reflection.
5. Ensure access to regular clinical supervision and mentorship across the MDT.
6. Promote peer support and structured debriefing after distressing events.
7. Provide training on communication skills, recognition of burnout and distress, coping strategies and self-care.
8. Facilitate access to confidential mental health support for staff experiencing significant distress.
9. Encourage individual self-care - healthy boundaries, adequate rest, peer support - and practical, low-resource wellbeing strategies where formal programmes are not feasible.
10. Demonstrate leadership commitment through policy, resource allocation and visible support for staff wellbeing.

This preview summarises Domain 7 only. The full Indian Guidelines for Psychosocial Care in Pediatric Oncology include comprehensive risk-factor detail, training curricula, and detailed implementation guidance for resource-limited settings. The complete guideline document is available on request from the guideline working group / corresponding author (daruvala91@gmail.com).

Domain 8

Special Psychosocial Considerations in Pediatric Hematopoietic Stem Cell Transplant (HSCT)

This domain covers four phases of the HSCT journey:

PRE-TRANSPLANT	CONDITIONING & ISOLATION	EARLY RECOVERY & DISCHARGE	LONG-TERM RECOVERY / SURVIVORSHIP
Anticipatory anxiety, decisional burden, baseline assessment.	Loneliness, regression, acute distress.	Transition anxiety, caregiver responsibility.	Late effects, identity, reintegration.

Not always linear - families move between stability and crisis; reassess at every transition.

At a glance:

1. HSCT is one of the most intensive, high-risk treatments in pediatric oncology with medical, psychological, and social burden that are closely interconnected ("total pain").
2. The intensity and complexity of HSCT often warrant targeted psychosocial support from the outset, in addition to universal support; care should be individualised according to assessed need.
3. A documented psychosocial baseline assessment before conditioning begins should be an essential component of HSCT care, providing a basis for risk stratification, targeted intervention, and ongoing monitoring.

8.1 Phase-Specific Psychosocial Considerations

Phase	Key concerns	Focus of care
Pre-transplant	Anticipatory anxiety, decisional burden, information overload	Psychoeducation, baseline psychosocial assessment, realistic expectation-setting Coping preparation
Conditioning and isolation	Loneliness, Withdrawal or regression, acute distress, Loss of routine, caregiver strain	Emotional containment, Maintaining routine, structured play and education, Regular psychosocial check-ins, Caregiver support
Early recovery & discharge	Transition anxiety, Increased caregiver responsibility Hypervigilance, fear of complications	Discharge counselling, caregiver preparation and training, accessible follow-up and early psychosocial review
Long-term recovery / survivorship	Late effects, identity and body image concerns, school social reintegration, Ongoing family adjustment	Longitudinal psychosocial monitoring, reintegration planning, School and peer support, survivorship focused psychosocial care

Quick action - During protective isolation

Maintain: daily routine | School activities where possible | Play and recreational activities | Digital connection with family and peers | Daily emotional check-ins | Caregiver breaks and support.

Isolation protects the body - psychosocial care protects emotional wellbeing, connection, and a sense of normalcy.

Quick action - Preparing for discharge

Confirm caregivers understand: Warning signs requiring urgent review | Infection-prevention precautions | Medication schedule | Follow-up appointments | Emergency contacts | Available psychosocial support.

Safe discharge requires both medical readiness and psychosocial preparedness.

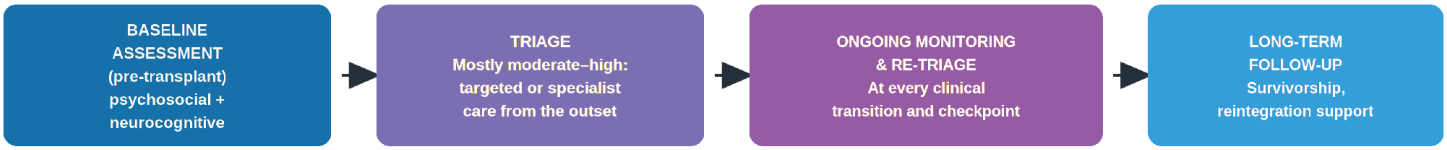
8.2 Baseline Assessment, Triage & Escalation

Quick action - Mandatory baseline, before HSCT

Complete before conditioning begins: Comprehensive psychosocial assessment | Family psychosocial risk assessment | Baseline neuropsychological assessment, where feasible and clinically indicated | Caregiver mental health screening | Financial and social work assessment preparation for the expected HSCT journey.

Every child undergoing HSCT should have a documented baseline psychosocial evaluation before conditioning begins.

The Psychosocial Care Pathway



Escalate or de-escalate dynamically — HSCT carries a high baseline psychosocial risk

Quick action - Escalate to specialist mental health care

Refer promptly when there is: Persistent or severe distress | Significant neurocognitive change or decline | Marked behavioural change | Caregiver burnout or significant caregiver distress | Family conflict that interferes with care | Persistent difficulty coping with HSCT demands.

HSCT carries a substantial psychosocial burden; escalate according to clinical need.

8.3 Child, Caregiver & Reintegration Considerations

CHILD - EMOTIONAL & DEVELOPMENTAL	ADOLESCENT-SPECIFIC	CAREGIVER & FAMILY
Distress & coping, developmental disruption, loss of routine	Identity and autonomy, body image, future and life-planning concerns *See also: Adolescents & Young Adults (Introduction).*	Caregiver burnout, role strain, separation and isolation, sibling needs, Family communication

Quick action - School reintegration

Plan jointly with family, school, and treating team. Discuss: Phased return | Fatigue and symptom management | Academic accommodations | Peer education where appropriate | Ongoing emotional support.

Successful reintegration begins before the first day back at school.

10 Key Action Points

1. Conduct a comprehensive psychosocial baseline assessment before conditioning begins, with neurocognitive assessment where feasible and clinically indicated.
2. Prepare CAYA and families for the HSCT journey through psychoeducation, realistic expectation-setting and coping preparation.
3. Implement structured, repeated psychosocial screening across HSCT phases and key clinical transitions.
4. Recognise the substantial psychosocial burden of HSCT and ensure timely access to targeted and specialist care according to need.
5. During protective isolation, maintain daily routine, play, schooling and digital connection with family and peers, with daily emotional check-ins.
6. Support caregivers with breaks, practical help and screening for caregiver burnout and distress.
7. Prepare for discharge with caregiver education on warning signs, infection prevention, medications, follow-up and available psychosocial support.
8. Plan school reintegration jointly with the family, school and treating team, including phased return and academic accommodations.
9. Provide family-centred, developmentally appropriate care for the child, caregivers and siblings, including adolescent concerns about identity, body image and the future.
10. Integrate psychosocial care into HSCT services through MDT collaboration and continuity across transplant, recovery & survivorship.

This preview summarises Domain 8 only. The full Indian Guidelines for Psychosocial Care in Pediatric Oncology provide comprehensive HSCT checkpoint and risk-factor tables, assessment domains, monitoring and evaluation indicators, and systems-level guidance for the Indian context. The complete guideline document is available on request from the guideline working group / corresponding author (daruvala91@gmail.com).



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Indian Guidelines for Psychosocial Care in Paediatric Oncology

Developed by the Psychological and Social Support Task Force
Indian Childhood Cancer Initiative (ICCI)