

# GUIDELINES FOR IMPLEMENTING THE PEDIATRIC PSYCHOSOCIAL STANDARDS OF CARE

- † New assessment tools and interventions are continuously being developed and tested for youth and families; all assessment tools, interventions and resources should be culturally and linguistically appropriate.
- †† PubMed links are provided whenever they are available. Links are also provided for all resources and tools, when available.
- ††† These links do not imply endorsement of specific organizations, their products and services. We cannot guarantee the currency, accuracy, relevance, or completeness of information found on linked, external websites as these change over time. We recognize that most resources are US based and may not be applicable to other countries. There may be other appropriate resources not included in these guidelines that are available in other countries.



**Standard 1:**

Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial health care needs.

Actions	Strategies	Resources/Tools †††
<p><b>1. Conduct Systematic Assessments of the Youth and Family Psychosocial Health Care Needs.</b></p>	<p><b>Identify psychosocial providers who will conduct screening and assessment.</b></p> <ul style="list-style-type: none"> <li>• Utilize psychosocial professionals (e.g., social workers, psychologists) experienced in conducting systematic assessments.</li> <li>• Psychosocial providers should, along with the healthcare team, identify the process for screening and assessment that is feasible for their individual institutions.</li> <li>• Screening and assessments should preferably be conducted on-site.</li> <li>• For documentation of screening and assessment results, follow policies of the health system in which the practice is undertaken. These policies should be in accordance with ethical requirements of the professional and state and federal laws.</li> </ul> <p><b>Determine timetable of sequential assessment during and after treatment.</b></p> <ul style="list-style-type: none"> <li>• Refer to treatment protocol for timelines. Ideally, at beginning, during</li> </ul>	<p><b>References:</b></p> <p>Kazak AE, DiDonato S, Schneider, S, et al. Assessing family psychosocial assessment risks in pediatric cancer: In Abrams AN, Muriel AL &amp; Wiener L, Eds). <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 51-65.</p> <p>Cohen LL, La Greca AM, Blount RL, et al. (Eds.) Introduction to special issue: Evidence-based assessment in pediatric psychology (Special issue). <i>J Pediatr Psychol</i>. 2008; 33,(9):911-915.  <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2639490/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2639490/</a></p>

Actions	Strategies	Resources/Tools †††
	<p>and end of treatment with long-term follow-up.</p> <p><b>Establish procedures for most effective use of and feedback from assessment results in treatment planning.</b></p> <ul style="list-style-type: none"> <li>Information relevant to the assessment question will be shared with staff directly involved and in person with parents. Procedure will balance information sharing with need for confidentiality, e.g., charting procedures, meetings and rounds.</li> </ul> <p><b>Select assessment tools based on clinical question or protocol.</b> (e.g., brief screening, more in-depth assessment; clinical interviews, evidence-based measures)</p> <ul style="list-style-type: none"> <li>Determine most effective modality for administering tools (paper and pencil, online, CAT, EMR, etc.).</li> </ul>	<p>Use evidence-based, psychometrically sound measures, and/or formal and informal clinical interviews that address psychosocial functioning.</p> <p>Examples of evidence-based brief screening and assessment Tools include:</p> <p><b>Youth:</b></p> <ul style="list-style-type: none"> <li><b>Pediatric Distress Thermometer (DT)</b> – The DT screens for distress on a visual analog scale designed to appear as a thermometer. It generates a 1 to 10 unidimensional rating of distress in children with cancer and parent proxy report, including a problem checklist addressing emotional, physical, practical, social, and spiritual concerns. SPatel@coh.org</li> <li><b>PedsQL General Core Scales</b> – Child and Parent Proxy measures physical, emotional, social and school functioning. Pedsql.org</li> <li><b>PROMIS Pediatric Mental Health Measures</b> – Child and parent proxy measures of Global Health (physical and mental health) as well as specific domains: emotional distress, anxiety, depression, anger, positive and negative affect) – HealthMeasures.net</li> <li><b>NIH Toolbox Emotion Measures (Child and Parent Proxy)</b> – Neuro-behavioral measures of cognitive and emotional functioning (Negative affect, psychological wellbeing, Stress and Self-Efficacy, Social Relationships) – HealthMeasures.net</li> </ul>

Actions	Strategies	Resources/Tools †††
		<p><b>Parent/Family:</b></p> <ul style="list-style-type: none"> <li>• <b>The Psychosocial Assessment Tool (PAT 3.0)</b> – A standardized parent self-report of psychosocial risk in families of children with cancer assessing family functioning, social support, acute stress, anxiety, child behavior and sibling’s problems.</li> <li>• <b>Distress thermometer for parents (DT-P)</b> – A standardized tool that generates a 1 to 10 unidimensional rating of distress in parents of children with chronic illness as a general checklist measure addressing emotional, physical, practical, social, and spiritual concerns.</li> <li>• <b>PROMIS Mental Health Adult Measures</b> <a href="http://www.healthmeasures.net">http://www.healthmeasures.net</a></li> <li>• <b>NIH Toolbox Adult Measures</b> <a href="http://www.healthmeasures.net/explore-measurement-systems/nih-toolbox">http://www.healthmeasures.net/explore-measurement-systems/nih-toolbox</a></li> </ul>

**Standard 2:**

Youth with brain tumors and others at high risk for neuropsychological deficits as a result of their cancer treatment are monitored for neuropsychological functioning during and after treatment.

Actions	Strategies	Resources/Tools †††
<p><b>2. Monitor/ Assess youth with brain tumors and/or those who receive CNS directed therapies for neuro-psychological deficits.</b></p>	<p><b>Train pediatric cancer team in screening procedures</b> that can identify youth with risk factors or acute mental status changes.</p> <p><b>Prioritize timing of neuropsychological monitoring/assessment as an essential part of acute and late effects care (e.g., during treatment).</b></p> <ul style="list-style-type: none"> <li>• If monitoring during treatment led to assessment, repeat assessment after treatment if/when clinically indicated. Otherwise, repeat assessment if clinically indicated during survivorship, monitoring at 2-3 years after treatment.</li> </ul> <p><b>Conduct neurocognitive screening and testing and refer to neuropsychology if more detailed assessment is needed.</b></p> <ul style="list-style-type: none"> <li>• If a full neuropsychological assessment is indicated, and a neuropsychologist is not available, create a partnership with existing pediatric neuropsychological providers from other clinical services (For example, pediatric neurology) or maintain a database of local</li> </ul>	<p>Monitoring tools may include parent/school/child report, standardized check-lists or questionnaires, and/or brief mental status or cognitive screening.</p> <p>Examples of monitoring tools that can be used for screening include:</p> <ul style="list-style-type: none"> <li>• <b>Vanderbilt Assessment Scale</b></li> <li>• <b>Colorado Learning Differences Questionnaire</b></li> <li>• <b>Bayley Scales of Infant Development Screening Test-III/IV</b></li> <li>• <b>Reynolds Intellectual Screening Test-2</b></li> </ul> <p>Note: Measures used should be reliable and valid for the clinical population.</p> <p><b>Additional Reading Material</b>            Patel SK, Schulte F, Kelly NC, et al. Neurocognitive late effects in children with cancer: In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 157-174.</p>

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	<p>neuropsychologists outside of the hospital system.</p> <p><b>Schedule a time for parents/caregivers to meet with the neuropsychologist to learn about the outcome from the assessment.</b></p> <ul style="list-style-type: none"> <li>• When appropriate, interventions should be provided (including recommendations for both home and school). (See Standard 11)</li> <li>• Reimbursement for neuropsychological monitoring and assessment services vary by state. Collaborate with social work, hospital billing and connect with community cancer support networks for coverage for the costs of monitoring/assessment, if cost is preventing neuropsychological services.</li> </ul>	

**Standard 3:**

Psychological follow-up in survivorship should occur annually for all long-term survivors of a childhood cancer.

Actions	Strategies	Resources/Tools †††
<p><b>3a. Provide youth and young adult survivors and their parents with anticipatory guidance on the need for life-long follow-up care by the time treatment ends and repeated at each follow-up visit.</b></p>	<p><b>Near the end of active treatment, youth and young adult survivors should meet with their treatment team</b> to receive a summary of care received and be advised on the importance of yearly (at minimum) LTFU care visits.</p> <p><b>Provide a survivor care plan.</b></p> <ul style="list-style-type: none"> <li>• A survivor care plan should include coordination between LTFU team and primary care providers and transition planning to adult-based providers.</li> <li>• If the survivor did not have a survivor care plan, work with the medical team to create one. This should be communicated to both the survivor and family and reviewed annually.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Health Links from COG, LTFU guidelines</b> - <a href="https://www.gottransition.org/">https://www.gottransition.org/</a></li> <li>• <b>Passport to Care</b> - <a href="https://passportforcare.org/">https://passportforcare.org/</a></li> <li>• <b>LTFU guidelines</b> - Poplack DG, Fordis M, Landier W, et al. Childhood cancer survivor care: development of the Passport for Care. <i>Nat Rev Clin Oncol.</i> 2014;11(12):740–750. doi:10.1038/nrclinonc.2014.175 <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5142740/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5142740/</a></li> <li>• <b>Transition to adult care</b> - <a href="https://www.gottransition.org/">https://www.gottransition.org/</a></li> <li>• <b>National Cancer Institute: Care for Childhood Cancer Survivors</b> - <a href="https://www.cancer.gov/about-cancer/coping/survivorship/child-care">https://www.cancer.gov/about-cancer/coping/survivorship/child-care</a></li> </ul>
<p><b>3b. Provide yearly psychosocial follow-up with long term survivors to detect and address psychological, social,</b></p>	<p><b>Identify a member(s) of the health care team that will see and monitor the psychosocial needs of the survivors after treatment has ended.</b></p> <p><b>Determine how psychosocial care will be monitored</b> (For example, Standardized psychosocial assessment(s)) and the specific domains to be assessed.</p>	<ul style="list-style-type: none"> <li>• <b>COG Survivorship Guidelines</b> - <a href="http://www.survivorshipguidelines.org/">http://www.survivorshipguidelines.org/</a></li> </ul> <p><b>General and Psychosocial Information:</b></p> <ul style="list-style-type: none"> <li>• <b>Diet and Physical Activity</b> (<a href="#">English</a>) (<a href="#">Spanish</a>) (<a href="#">Chinese Traditional TC</a>) (<a href="#">Chinese Simplified SC</a>) Educational Issues (<a href="#">English</a>) (<a href="#">Spanish</a>) (<a href="#">Chinese Traditional TC</a>) (<a href="#">Chinese Simplified SC</a>)</li> <li>• <b>Emotional Issues</b> (<a href="#">English</a>) (<a href="#">Spanish</a>) (<a href="#">Chinese Traditional TC</a>) (<a href="#">Chinese Simplified SC</a>)</li> </ul>



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<p><b>academic/vocational difficulties and risky health behaviors.</b></p>	<p><b>Obtain comprehensive information on the psychosocial functioning of long-term survivors of child and adolescent cancers.</b></p> <ul style="list-style-type: none"> <li>• This can be done in a long-term follow-up (LTFU) care clinics or with existing hospital oncology or outpatient primary care providers during dedicated long-term follow-up visits with referrals for psychosocial care as needed.</li> </ul> <p><b>Include in the Annual LTFU assessment:</b></p> <ul style="list-style-type: none"> <li>• Physical health</li> <li>• Academic achievement</li> <li>• Employment</li> <li>• Social/family relationships and resources</li> <li>• Mental health: Psychosocial distress, anxiety, depression</li> <li>• Posttraumatic stress symptoms</li> <li>• Suicidality</li> <li>• Substance use</li> </ul> <p><b>Provide annual training and updates to providers at your center on psychosocial survivorship issues, update with new research findings.</b></p>	<ul style="list-style-type: none"> <li>• <b>Finding and Paying for Healthcare</b> (<u><a href="#">English</a></u>) (<u><a href="#">Spanish</a></u>) (<u><a href="#">Chinese Traditional TC</a></u>) (<u><a href="#">Chinese Simplified SC</a></u>)</li> <li>• <b>Introduction to Long-Term Follow-Up</b> (<u><a href="#">English</a></u>) (<u><a href="#">Spanish</a></u>) (<u><a href="#">Chinese Traditional TC</a></u>) (<u><a href="#">Chinese Simplified SC</a></u>)</li> <li>• <b>Survivors 12-17 -- Beck Youth Scales Anxiety, Depression -</b> <u><a href="https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildMentalHealth/BeckYouthInventories-SecondEditionForChildrenandAdolescents(BYI-II)/BeckYouthInventories-SecondEditionForChildrenandAdolescents(BYI-II).aspx">https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildMentalHealth/BeckYouthInventories-SecondEditionForChildrenandAdolescents(BYI-II)/BeckYouthInventories-SecondEditionForChildrenandAdolescents(BYI-II).aspx</a></u></li> <li>• <b>Childhood cancer survivors 18 or older-- BSI-18 -</b> <u><a href="https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Personality-%26-Biopsychosocial/Brief-Symptom-Inventory-18/p/100000638.html">https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Personality-%26-Biopsychosocial/Brief-Symptom-Inventory-18/p/100000638.html</a></u></li> </ul> <p><b>Additional Recommended Assessment Tools from Standard #1</b></p> <ul style="list-style-type: none"> <li>• <b>PedsQL General Core Scales</b> – Child and Parent Proxy measures physical, emotional, social and school functioning. Pedsq.org</li> <li>• <b>PROMIS Pediatric Mental Health Measures-</b> Child and parent proxy measures of Global Health (physical and mental health) as well as specific domains: emotional distress, anxiety, depression, anger, positive affect) – HealthMeasures.net</li> </ul>

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	<p><b>Offer survivors intervention as needed and as available.</b></p> <ul style="list-style-type: none"> <li>• Include opportunities to meet with other survivors, either at the cancer center or through community groups and programs.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>PROMIS Adult Mental Health Measures</b>- Global Health (physical and mental health) as well as specific domains: emotional distress, anxiety, depression, anger, positive affect) – HealthMeasures.net</li> <li>• <b>NIH Toolbox Emotion Measures</b> (Child and Parent Proxy) – neuro-behavioral measures of cognitive and emotional functioning (Negative affect, psychological wellbeing, Stress and Self-Efficacy, Social Relationships) – HealthMeasures.net</li> </ul> <p><b>Long-term follow-up Care Plan System:</b> Devine KA, Viola AS, Coups EJ, et al. Digital Health Interventions for Adolescent and Young Adult Cancer Survivors. <i>JCO Clin Cancer Inform.</i> 2018;2:1–15. <a href="https://www.ncbi.nlm.nih.gov/pubmed/30652583">https://www.ncbi.nlm.nih.gov/pubmed/30652583</a></p> <p><b>Adolescent and Young Adult information:</b> <a href="https://www.cancer.gov/types/aya">https://www.cancer.gov/types/aya</a></p> <p><b>See Recommended Interventions in:</b> †† Steele AC, Mullins LL, Mullins AJ, et al. Psychosocial Interventions and Therapeutic Support as a Standard of Care in Pediatric Oncology. <i>Pediatr Blood Cancer.</i> 2015;62 Suppl 5:S585–S618. doi:10.1002/pbc.25701 <a href="https://www.ncbi.nlm.nih.gov/pubmed/26700919">https://www.ncbi.nlm.nih.gov/pubmed/26700919</a></p> <p><b>Other Organizations Include:</b> †††</p> <ul style="list-style-type: none"> <li>• <b>American Society of Clinical Oncology (ASCO)- Cancer in Young Adults:</b> <a href="https://www.cancer.net/navigating-cancer-care/young-adults-and-teenagers">https://www.cancer.net/navigating-cancer-care/young-adults-and-teenagers</a></li> </ul>

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		<ul style="list-style-type: none"> <li>• <b>Children’s Oncology Group, Coping with Cancer:</b>  <a href="https://childrensoncologygroup.org/index.php/81-coping-with-cancer">https://childrensoncologygroup.org/index.php/81-coping-with-cancer</a></li> <li>• <b>LIVESTRONG Adolescents and Young Adults:</b>  <a href="https://www.livestrong.org/we-can-help/young-adults">https://www.livestrong.org/we-can-help/young-adults</a></li> <li>• <b>Stupid Cancer:</b>  <a href="https://stupidcancer.org/">https://stupidcancer.org/</a></li> <li>• <b>Ulman Foundation:</b>  <a href="https://ulmanfoundation.org/">https://ulmanfoundation.org/</a></li> </ul> <p><b>Additional Reading Material:</b>  Liptak CC, Chow C, Zhou ES, et al. Psychosocial care for pediatric cancer survivors: In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 265-290.</p>

**Standard 4:**

All youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed.

Actions	Strategies	Resources/Tools †††
<p><b>4. Ensure youth and their families are provided appropriate psychosocial interventions and psychiatry referrals as needed.</b></p>	<p><b>To ensure provision of psychosocial interventions the following on-going supports should be implemented:</b></p> <ul style="list-style-type: none"> <li>• Supportive Care Professionals: Centers should make a commitment to having at least one staff member with education or training in supportive care (social work, psychology, or counseling) to assist youth and families.</li> <li>• Training: Staff providing psychosocial care should have training in family centered care, evidence-based interventions, empathic listening, communication, child development, problem solving, and health literacy, among others. (See Standard 15)</li> <li>• Interventions guided by assessment: Interventions and referrals should be tied to the assessment of youth and family adjustment to illness and any premorbid risk factors.</li> <li>• Cultural Sensitivity: Interventions should be culturally sensitive and available to non-English speaking families.</li> </ul>	<p><i>* Note: New interventions are continuously being developed and tested for youth and families, but many research reports have yet to be published and fewer interventions have been widely disseminated.</i></p> <p><b>Examples of interventions with empirical support within the pediatric cancer population include:</b></p> <ul style="list-style-type: none"> <li>• <b>Cognitive Behavior Therapy</b> – CBT (parent or child)</li> <li>• <b>Bright IDEAS Problem Solving Skills therapy (PSST)</b>  <a href="https://rtips.cancer.gov/rtips/programDetails.do?programId=546012">https://rtips.cancer.gov/rtips/programDetails.do?programId=546012</a>  <a href="https://open.learnbrightideas.org/">https://open.learnbrightideas.org/</a>; Available in English and Spanish</li> <li>• <b>Surviving Cancer Competently Intervention Program - SCCIP (parent)</b> -  <a href="https://rtips.cancer.gov/rtips/programDetails.do?programId=102875">https://rtips.cancer.gov/rtips/programDetails.do?programId=102875</a></li> </ul> <p><b>Examples of other interventions and resources used frequently within the pediatric cancer population but with limited or undetermined empirical support:</b></p> <ul style="list-style-type: none"> <li>• Supportive counseling</li> <li>• Family therapy</li> <li>• Play therapy</li> <li>• Support groups</li> <li>• Bibliotherapy</li> </ul>

Actions	Strategies	Resources/Tools †††
	<ul style="list-style-type: none"> <li>• Referral Networks: Centers can build strong referral bases within the community through community support agencies, social workers, psychologists, psychiatrists, religious support, and can direct youth and families to these trained professionals if such services are not available at the center.</li> <li>• Community Education and Consultation: Centers can provide formal consultation services with local professionals to educate about the psychosocial needs of youth with cancer and their family members.</li> <li>• Multimedia Materials: Centers should ensure access to appropriate multimedia resources for both parents and youth throughout the course of illness, including, but not limited to, disease education, procedure preparation videos, games, books, and handouts.</li> </ul>	<p><b>Examples of Cancer Specific Coping Tools Include:</b></p> <ul style="list-style-type: none"> <li>• <b>Cellie Coping Kit (youth)</b> - <a href="https://www.chop.edu/health-resources/cellie-cancer-coping-kit">https://www.chop.edu/health-resources/cellie-cancer-coping-kit</a></li> <li>• <b>ShopTalk (youth)</b> - <a href="https://ccr.cancer.gov/Pediatric-Oncology-Branch/psychosocial/education">https://ccr.cancer.gov/Pediatric-Oncology-Branch/psychosocial/education</a></li> </ul> <p><b>Additional Resources:</b></p> <ul style="list-style-type: none"> <li>• <b>The National Cancer Institute</b> - <a href="https://www.cancer.gov/pediatric-adult-rare-tumor/support/caring-children-cancer">https://www.cancer.gov/pediatric-adult-rare-tumor/support/caring-children-cancer</a></li> </ul> <p><b>Additional Reading Materials:</b></p> <p>Mullins LL, Tackett, AP, Suorsa, KI. Psychotherapeutic Modalities for Children. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 81-106.</p> <p>Armington CH, Peach HE, Hopkinson S. Preparation, Education, and Procedural Support. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 107-118.</p> <p>Sourkes B, Kazak AE, Wiener L. Psychotherapeutic Interventions. In Wiener LS, Pao M, Kazak AE, Kupst MJ, Patenaude AF, Arceci R, Eds. <i>Pediatric Psycho-Oncology: A Quick Reference on the Psychosocial Dimensions of Cancer Symptom Management</i>. Oxford University Press; 2015: 177-186.</p>

Actions	Strategies	Resources/Tools †††
		<p data-bbox="1073 261 1881 440">Hardy KK, Grootenhuis MA. Electronic Interventions. In Wiener LS, Pao M, Kazak AE, Kupst MJ, Patenaude AF, Arceci R, Eds. <i>Pediatric Psycho-Oncology: A Quick Reference on the Psychosocial Dimensions of Cancer Symptom Management</i>. Oxford University Press; 2015: 187-198</p> <p data-bbox="1073 480 1881 659">Sahler OJZ, McClafferty H, Rosen MA. Integrative Oncology. In Wiener LS, Pao M, Kazak AE, Kupst MJ, Patenaude AF, Arceci R, Eds. <i>Pediatric Psycho-Oncology: A Quick Reference on the Psychosocial Dimensions of Cancer Symptom Management</i>. Oxford University Press; 2015: 199-218</p>

**Standard 5:**

Assessment of risk for financial hardship should be incorporated at time of diagnosis for all pediatric oncology families. Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship or bereavement.

Actions	Strategies	Resources/Tools †††
<p><b>5a. Assessment of risk for financial hardship is incorporated at the time of diagnosis for all pediatric oncology families.</b></p>	<p><b>Obtain comprehensive screening information on the financial resource needs of parents/caregivers.</b></p> <ul style="list-style-type: none"> <li>Assessments should occur throughout the cancer treatment trajectory and into survivorship and bereavement.</li> </ul> <p><b>Utilize a financial hardship assessment tool.</b></p> <ul style="list-style-type: none"> <li>The tool should be employed at the time of diagnosis and at intervals throughout the cancer treatment trajectory and into survivorship or bereavement. The first assessment should occur within the first month following diagnosis.</li> </ul> <p><b>Consider direct treatment-related costs:</b></p> <ul style="list-style-type: none"> <li>Hospital/physician fees, medications, equipment, aid devices such as prostheses and wheelchairs.</li> </ul> <p><b>Consider indirect treatment-related costs:</b></p>	<p><b>Screening Tool Examples and Resources:</b></p> <ul style="list-style-type: none"> <li><b>Social Interventions Research &amp; Evaluation Network (SIREN)</b> - <a href="https://sirenetwork.ucsf.edu/tools-resources/screening-tools">https://sirenetwork.ucsf.edu/tools-resources/screening-tools</a></li> <li><b>Health Leads</b> - <a href="https://healthleadsusa.org/resources/the-health-leads-screening-toolkit/">https://healthleadsusa.org/resources/the-health-leads-screening-toolkit/</a></li> <li><b>CMS (Centers for Medicare and Medicaid Services)</b> - <a href="https://innovation.cms.gov/Files/worksheets/ahcm-screeningtool.pdf">https://innovation.cms.gov/Files/worksheets/ahcm-screeningtool.pdf</a></li> <li><b>National Association of Community Health Centers and Partners, National Association of Community Health Centers, Association of Asian Pacific Community Health Organizations, Association OPC, Institute for Alternative Futures. (2017). PRAPARE</b> - <a href="http://www.nachc.org/research-and-data/prapare/">http://www.nachc.org/research-and-data/prapare/</a></li> </ul>

Actions	Strategies	Resources/Tools †††
	<ul style="list-style-type: none"> <li>• Unpaid leaves from employment or altered work schedules resulting in financial consequences, loss of savings, loss of healthcare benefits due to change in employment status.</li> <li>• Travel and parking expenses for clinic visits and hospital admissions, food, accommodation, childcare for siblings, communication-related costs, comfort items for their child during hospital/clinic visits.</li> </ul> <p><b>Assess the financial burden for parents when their child is at end-of-life:</b></p> <ul style="list-style-type: none"> <li>• Pain medications, respite care, special equipment needs, anticipated funeral costs and financial needs during bereavement.</li> </ul> <p><b>Assess the financial burden of childhood cancer survivors:</b></p> <ul style="list-style-type: none"> <li>• Unemployment/under-employment and dependent living.</li> </ul> <p><b>Provide targeted referrals for financial counseling.</b></p>	<p><b>Additional Resources:</b></p> <ul style="list-style-type: none"> <li>• Financial counselling (e.g., social work, certified financial counselor/planner or other appropriate discipline)</li> </ul>



Actions	Strategies	Resources/Tools †††
	<ul style="list-style-type: none"> <li>• Consider applicable government, charitable, or Foundation supports.</li> <li>• Encourage parents to explore options through their employers (such as PFL and FMLA).</li> <li>• Encourage parents to navigate the income tax network so that they may take advantage of tax credits for medical expenses.</li> </ul> <p><b>Educate the medical team around the implications of financial burden on emotional distress in families.</b></p> <ul style="list-style-type: none"> <li>• This includes discussions around fear of stigmatization and encouraging members of the medical team to initiate conversations around financial burden/coping in order to normalize the experience.</li> </ul>	<ul style="list-style-type: none"> <li>• Applicable governmental, charitable, and Foundation supports (local/national organizations)</li> </ul> <p><b>Additional Reading Material:</b>  Gerhardt CA, Salley CG, Lehmann V. The impact of pediatric cancer on the family. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 143-156.</p> <p>Zadeh S, Golant M, Phillips F, et al. Resources Chapter. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 397-409.</p>
<p><b>5b. Provide longitudinal reassessment and intervention of financial risk occurs throughout the cancer treatment trajectory and into survivorship and bereavement.</b></p>		

**Standard 6:**

Parents and caregivers of youth with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, youth, and family well-being.

Actions	Strategies	Resources/Tools †††
<p><b>6a. Ensure assessment of parental coping and mental health needs at the time of diagnosis, at regular intervals, and at medically significant timepoints.</b></p>	<p><b>Implement routine culturally and linguistically appropriate assessments</b> of parental coping and mental health needs (e.g., anxiety, depression, adjustment, posttrauma stress symptoms) utilizing standardized screening tool(s) around the time of diagnosis.</p> <p><b>Establish a mechanism</b> for the pediatric oncology team to refer parents demonstrating significant distress to psychosocial clinician for further evaluation.</p> <p><b>Establish resources to help parents with a referral process.</b> For example, a listing of mental health providers who participate in their insurance plan and/or are familiar with childhood cancer and the emotional impact on the family.</p> <p><b>Consider resources applicable for parents</b> who do not have insurance, such as publicly funded mental health assessments and service delivery.</p>	<p><b>Examples of Assessment Tools with Empirical Support:</b></p> <ul style="list-style-type: none"> <li>• <b>Psychosocial Assessment Tool</b> – Kazak AE, Hwang W-T, Chen F-F, Askins MA, et al. Screening for family psychosocial risk in pediatric cancer: Validation of the Psychosocial Assessment Tool (PAT) Version 3. <i>J Pediatr Psychol.</i> 2018; 43(7):737-748. <a href="https://pubmed.ncbi.nlm.nih.gov/29509908/">https://pubmed.ncbi.nlm.nih.gov/29509908/</a></li> <li>• Kazak AE, Hwang W-T, Chen F-F, Askins MA, et al. Validation of the Spanish version of the Psychosocial Assessment Tool (PAT) in pediatric cancer. <i>J Pediatr Psychol.</i> 2018; 43(10):1104-1113. <a href="https://pubmed.ncbi.nlm.nih.gov/29982606/">https://pubmed.ncbi.nlm.nih.gov/29982606/</a></li> <li>• <b>Mental health history, symptoms of PTSS</b></li> <li>• <b>Parent Distress Thermometer</b> – Haverman L, VanOers H, Limperg PF, Hautzager BA, et al. Development and validation of the Distress Thermometer for parents of a chronically ill child. <i>J Pediatr.</i> 2013;163(4): 1140-1146.e2 <a href="https://www.sciencedirect.com/science/article/pii/S0022347613007245">https://www.sciencedirect.com/science/article/pii/S0022347613007245</a></li> <li>• <b>Brief adult mental health screeners for at risk parents ** links to PHQ 2 and PHQ –</b></li> <li>• PHQ-2: <a href="https://brightfutures.aap.org/Bright%20Futures%20Documents/PHQ-2%20Instructions%20for%20Use.pdf">https://brightfutures.aap.org/Bright%20Futures%20Documents/PHQ-2%20Instructions%20for%20Use.pdf</a> and</li> </ul>

Actions	Strategies	Resources/Tools †††
	<p><b>Also determine resources</b> that would be culturally and linguistically appropriate, such as immigrant aid or community based services.</p> <p><b>Establish standardized time points for re-assessment</b> (e.g., diagnosis, every 3 months, end of treatment, relapse, end-of-life, bereavement).</p>	<ul style="list-style-type: none"> <li>• PHQ-9: <a href="https://www.med.umich.edu/1info/FHP/practiceguides/depress/phq-9.pdf">https://www.med.umich.edu/1info/FHP/practiceguides/depress/phq-9.pdf</a></li> </ul>
<p><b>6b. Provide access to appropriate interventions to support parental coping and mental health as indicated.</b></p>	<p><b>Develop psychoeducational programming</b> for multidisciplinary pediatric oncology providers regarding providing effective communication and first line support to parents (Refer to Standard 15).</p> <ul style="list-style-type: none"> <li>• Develop capacity for pediatric psychosocial team to individually assess and address parent coping and mental health needs.</li> <li>• Develop parent support teaching sheets, and supportive and skills-based group interventions for parents.</li> <li>• Develop rapid referral process for adult mental health within the medical system of care (affiliated adult hospital/ clinic).</li> <li>• Develop relationships with adult psycho-oncology providers who may be</li> </ul>	<p><b>Examples of Interventions:</b></p> <ul style="list-style-type: none"> <li>• <b>Bright IDEAS Problem Solving Skills Training (PSST)</b> <a href="https://rtips.cancer.gov/rtips/programDetails.do?programId=546012">https://rtips.cancer.gov/rtips/programDetails.do?programId=546012</a> and <a href="https://open.learnbrightideas.org/">https://open.learnbrightideas.org/</a>; Available in English and Spanish</li> <li>• <b>Individual Cognitive Behavioral Therapy (CBT)</b></li> <li>• <b>Access to psychopharmacology</b></li> <li>• <b>Surviving Cancer Competently Intervention Program (SCCIP)</b> - <a href="https://rtips.cancer.gov/rtips/programDetails.do?programId=102875">https://rtips.cancer.gov/rtips/programDetails.do?programId=102875</a></li> </ul> <p><b>Examples of other interventions and resources used frequently within the pediatric cancer population but with limited or undetermined empirical support:</b></p> <ul style="list-style-type: none"> <li>• <b>Parent guidance/ Behavioral coaching</b></li> <li>• <b>Parent relaxation apps</b> – For example, Headspace, Calm, Breathe2relax <ul style="list-style-type: none"> <li>○ Teaching sheet on finding a local adult Mental Health professional</li> <li>○ Check with a Parent’s Primary Care Provider</li> </ul> </li> </ul>

Actions	Strategies	Resources/Tools †††
	<p>able to provide in person or telepsychiatry services – i.e. providers with an understanding of cancer treatment.</p> <ul style="list-style-type: none"> <li>• Create mechanism for parent to have own medical record number for individual treatment.</li> </ul>	<ul style="list-style-type: none"> <li>○ National Register of Health Providers in Psychology</li> <li>○ <b>Cancer Support Community</b> - <a href="https://www.cancersupportcommunity.org/find-support/cancer-support-helpline">https://www.cancersupportcommunity.org/find-support/cancer-support-helpline</a></li> <li>○ <b>Cancer Care</b> - <a href="https://www.cancercare.org/counseling">https://www.cancercare.org/counseling</a></li> <li>• <b>Support groups</b></li> <li>• <b>Parent-to-Parent Mentors</b></li> </ul> <p><b>Additional Resources:</b>  <a href="https://www.cancer.gov/pediatric-adult-rare-tumor/support/patients-caregivers">https://www.cancer.gov/pediatric-adult-rare-tumor/support/patients-caregivers</a></p> <p><b>Additional Reading Material:</b>  Gerhardt CA, Salley CG, Lehmann V. The impact of pediatric cancer on the family. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 143-156.</p>

**Standard 7:**

Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation, and be provided throughout the trajectory of cancer care.

Actions	Strategies	Resources/Tools †††
<p><b>7a. Provide psychoeducation and anticipatory guidance to youth and families, as appropriate for stage of treatment (i.e., initial diagnosis, ongoing treatment, end of therapy, relapse, survivorship, end-of-life, bereavement).</b></p>	<p><b>Identify team members who will be providing/can provide education and guidance</b> related to disease and treatment, hospitalization and procedures, and psychosocial adaptation. Psychoeducation and anticipatory guidance can be and likely will be provided by multiple disciplines; in fact, a team approach is recommended if staffing allows.</p> <p><b>Schedule regular meetings.</b> Youth and parents/caregivers should meet with psychosocial providers regularly for education and guidance. Scheduled meetings at transition points are important, as well as the ability to contact providers as needed for follow-up.</p> <p><b>Ensure access to educational resources.</b> Centers should have access to appropriate educational resources and multimedia materials for both caregivers and youth. These materials should explain and normalize the cancer experience and feelings associated with different stages of illness. They should include, but not be</p>	<p><i>*Note: New interventions may be in development, but research reports have yet to be published. Resources below are often used and may be helpful but many have limited empirical support. In addition, some currently available resources may change over time.</i></p> <p><b>Examples of Resources:</b> Written, visual, and tactile expressive and psychoeducational tools including:</p> <ul style="list-style-type: none"> <li>• <b>Children’s Oncology Website, Patient and Family Section</b> - <a href="https://www.childrensoncologygroup.org/index.php/patients-and-families">https://www.childrensoncologygroup.org/index.php/patients-and-families</a> (Reliable medical information disease and treatment written in lay terms, as well as sections on coping, school, grief, informed consent, and more).</li> <li>• <b>COG Healthlinks</b> - <a href="http://www.survivorshipguidelines.org/">http://www.survivorshipguidelines.org/</a> (Patient education handouts for survivors re: specific late effects and ways to enhance and protect health, e.g., Diet and Physical Activity, Dental Health, Heart Health), available in English and Spanish.</li> <li>• <b>Imaginary Friends Society</b> - <a href="https://www.imaginaryfriendsociety.com/">https://www.imaginaryfriendsociety.com/</a> (A series of short informational videos for children in both English and Spanish about disease, treatment, procedures, and common emotions).</li> </ul>

Actions	Strategies	Resources/Tools †††
	<p>limited to books, handouts, videos, medical play toys and dolls, and games.</p>	<p><b>Developmentally appropriate teaching tools for explaining disease, treatment, and procedures to children</b></p> <ul style="list-style-type: none"> <li>• <b>Cellie Coping Kit</b> - <a href="https://www.chop.edu/health-resources/cellie-cancer-coping-kit">https://www.chop.edu/health-resources/cellie-cancer-coping-kit</a></li> <li>• <b>Medikin Medical Doll</b> - <a href="https://legacyproductsinc.com/treatments/neuro-oncology-oncology-hematology">https://legacyproductsinc.com/treatments/neuro-oncology-oncology-hematology</a></li> </ul> <p><b>Books</b></p> <ul style="list-style-type: none"> <li>• <b>Magination Press</b> - <a href="https://www.apa.org/pubs/magination/browse?query=subject:Health+and+Medical+Issues">https://www.apa.org/pubs/magination/browse?query=subject:Health+and+Medical+Issues</a></li> </ul> <p><b>Games</b></p> <ul style="list-style-type: none"> <li>• <b>ShopTalk</b> – A therapeutic game designed to help professionals have conversations with pediatric and adolescents about living with cancer - <a href="https://ccr.cancer.gov/Pediatric-Oncology-Branch/psychosocial/education">https://ccr.cancer.gov/Pediatric-Oncology-Branch/psychosocial/education</a></li> <li>• <b>Nanobot’s Revenge</b> – An online video game where players become a robot to “blast away cancer” <a href="https://www.re-mission2.org/">https://www.re-mission2.org/</a></li> </ul> <p><b>Fertility</b></p> <ul style="list-style-type: none"> <li>• <b>Fertile Hope</b> - <a href="https://www.livestrong.org/we-can-help/livestrong-fertility">https://www.livestrong.org/we-can-help/livestrong-fertility</a></li> <li>• <b>Save My Fertility</b> - <a href="http://savemyfertility.org/">http://savemyfertility.org/</a></li> <li>• <b>Lets Take Charge</b> - <a href="https://www.letstakecharge.org/">https://www.letstakecharge.org/</a></li> <li>• <b>Financial Resources</b> - <a href="http://www.fertilitywithinreach.org/">http://www.fertilitywithinreach.org/</a> <a href="http://www.reprotech.com">www.reprotech.com</a> and <a href="http://www.livestrong.org/fertility">www.livestrong.org/fertility</a></li> </ul> <p><b>Advance Care Planning</b> – Refer to Standard 13</p>

Actions	Strategies	Resources/Tools †††
		<p><b>Psychosocial Intervention Resources</b> – Refer to Standard 4</p> <p><b>Painful Procedure Resources</b> – Refer to Standard 8</p> <p><b>Additional Reading Material:</b>  Brand SR, Tarquini S, Mack JW. Communication in the Pediatric Oncology Setting. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 7-24.</p> <p>Kazak AK, DiDonato S, Schneider S, et al. Assessing Family Psychosocial Risks in Pediatric Cancer. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 51-66.</p> <p>Kupst MJ, Patenaude AF. (2016). Coping and adaptation in pediatric cancer. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 67-80.</p>

Actions	Strategies	Resources/Tools †††
<p><b>7b. Tailor psycho-education and guidance to youth/family understanding of diagnosis and treatment, youth’s developmental level, family culture and language of origin, and how the youth and family receive information best.</b></p>	<p><b>Assess and document youth and family information needs and preferences.</b>          Psychosocial assessments conducted by psychosocial team members (e.g., social workers, psychologists, child life specialists) should include screening for health literacy and will be valuable in understanding individual needs and in guiding youth and family education.</p> <p><b>Education/information should be provided in preferred and/or multiple formats</b> (i.e., verbal, written, visual) in the youth and family’s language of origin or with the use of medical interpretation.</p> <p><b>Provide Referrals.</b> When appropriate, additional intervention, recommendations, referrals, and hospital and community resources should be provided.</p>	



**Standard 8:**

All youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth should receive psychological intervention for invasive medical procedures.

Actions	Strategies	Resources/Tools †††
<p><b>8a. Assess a youth's distress before invasive medical procedures.</b></p>	<p><b>Assess youth needs, preferences, and characteristics.</b></p> <ul style="list-style-type: none"> <li>• Consider youth's developmental and cognitive abilities, affective state and traits, as well as preference for provision of medical information (details vs. "big picture").</li> <li>• Consult with caregiver, especially before the first invasive medical procedure, in order learn about previous procedure experience(s), youth temperament, any sensory concerns, learning style (visual, auditory preferences), and the appropriateness, timing and desire for interventions.</li> </ul>	<p><b>Assessments of Distress</b></p> <ul style="list-style-type: none"> <li>• <b>Child and Parent Assessment</b> – See standard #1</li> <li>• <b>Psychosocial Risk Assessment in Pediatrics (PRAP)</b> - <a href="https://www.childlife.org/resources/for-child-life-specialists/prap">https://www.childlife.org/resources/for-child-life-specialists/prap</a></li> <li>• <b>Pediatric Distress Thermometer</b> SPatel@coh.org</li> <li>• <b>The Children's Fear Scale</b> - <a href="https://www.uoguelph.ca/pphc/sites/default/files/Childrens-Fear-Scale-pdf2.pdf">https://www.uoguelph.ca/pphc/sites/default/files/Childrens-Fear-Scale-pdf2.pdf</a> <a href="https://www.researchgate.net/publication/51537543_Children's_Fear_During_Procedural_Pain_Preliminary_Investigation_of_the_Children's_Fear_Scale">https://www.researchgate.net/publication/51537543_Children's_Fear_During_Procedural_Pain_Preliminary_Investigation_of_the_Children's_Fear_Scale</a></li> </ul>
<p><b>8b. Provide anticipatory guidance.</b></p>	<p><b>Provide youth with information and guidance about procedure.</b></p> <ul style="list-style-type: none"> <li>• Encourage parent, nurse, doctor, and trained staff (Child Life Specialist, Psychologist, Social Worker) to communicate with youth to discuss procedure in advance depending on</li> </ul>	<p><b>Prep books/multimedia</b></p> <ul style="list-style-type: none"> <li>• <b>Child Life Specialists</b> - <a href="https://www.childlife.org/resources/for-child-life-specialists/child-life-resource-library">https://www.childlife.org/resources/for-child-life-specialists/child-life-resource-library</a></li> <li>• <b>Medical Play Kits</b> - <a href="https://www.chop.edu/health-resources/medical-play">https://www.chop.edu/health-resources/medical-play</a></li> <li>• <b>Medical Dolls</b> - <a href="https://legacyproductsinc.com/">https://legacyproductsinc.com/</a></li> <li>• <b>Gabes Chemo Duck</b> - <a href="https://chemoduck.org">https://chemoduck.org</a></li> </ul>

Actions	Strategies	Resources/Tools †††
	<p>developmental level and level of anxiety.</p> <ul style="list-style-type: none"> <li>• Encourage family members and providers to impart open, honest communication about upcoming procedure, implementing the ‘5 sense’ approach to preparation (e.g., addressing all five of senses – see, taste, smell, hear, feel).</li> <li>• Provide youth with access to procedural equipment/procedural preparation materials (e.g., multimedia, books)/medical play.</li> </ul> <p><b>Coach caregivers in strategies to use with youth during procedure(s)</b></p> <ul style="list-style-type: none"> <li>• Encourage family members and providers to use strategies consistent with the individual youth’s style such as humor, praise, distraction, specific commands, and talking with rather than at the youth in pre-procedure communication with the youth.</li> <li>• Discuss comforting positions with caregivers.</li> </ul>	<p><b>Additional Resources:</b></p> <ul style="list-style-type: none"> <li>• <b>National Cancer Institute</b> - <a href="https://www.cancer.gov/pediatric-adult-rare-tumor/support/caring-children-cancer#help-prepare-your-child-for-procedures">https://www.cancer.gov/pediatric-adult-rare-tumor/support/caring-children-cancer#help-prepare-your-child-for-procedures</a></li> </ul> <p><b>Additional Reading Material:</b>  Armington CH, Peach HE, Hopkinson S. Preparation, Education, and Procedural Support. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 107-118.</p>

Actions	Strategies	Resources/Tools †††
	<p><b>Give youth choice and control.</b></p> <ul style="list-style-type: none"> <li>• Give youth as much developmentally appropriate information and choice where possible if the youth finds this helpful (i.e., allow youth to help, watch procedure, take a break if needed). Encourage youth’s role (job) during the procedure to promote effective coping.</li> <li>• Create a coping plan or a pain (poke) plan that includes interventions listed below.</li> </ul> <p><b>Provide information/education in preferred format.</b></p> <ul style="list-style-type: none"> <li>• Consider culture and language when preparing the youth for procedures and providing educational materials.</li> </ul> <p><b>Provide appropriate referrals.</b></p> <ul style="list-style-type: none"> <li>• Consult/refer to child life or psychology when more intensive procedural preparation is warranted, such as in the case of extreme anxiety, fear, or prior negative experience.</li> </ul>	

Actions	Strategies	Resources/Tools †††
<p><b>8c. Reduce a youth’s distress before invasive medical procedures by providing developmentally appropriate education, information, support, and psychological/behavioral intervention tailored to the specific needs and preferences of individual youth and families and provided throughout the trajectory of cancer care.</b></p>	<p><b>Provide the youth with interventions to use prior to, during, and after procedure(s).</b></p> <ul style="list-style-type: none"> <li>• Distraction (tablets, books, music, toys, pet therapy, virtual reality, blowing bubbles, conversations with parents)</li> <li>• Cognitive-behavioral techniques (deep breathing, relaxation, distraction, psychoeducation, behavioral rehearsal, modeling, imagery, hypnosis)</li> </ul> <p><b>Teach parents and youth strategies to reduce youth and parental anxiety.</b></p> <p><b>Re-visit and tailor needs as developmental or support needs change with changes in or response to treatment or previous negative procedure experience(s).</b></p> <p><b>Consider tools to reduce pain and anxiety with injections such as EMLA cream, coping devices (such as buzzy, shot blocker, freeze spray).</b></p> <ul style="list-style-type: none"> <li>• Collaborate with medical providers to discuss need for referral for combined pharmacologic and psychological interventions for more painful procedures.</li> </ul>	<p><b>Descriptive multimedia resources</b> (showing procedures and methods to reduce distress)</p> <ul style="list-style-type: none"> <li>• <b>Coping Club videos</b> - <a href="http://copingclub.com/">http://copingclub.com/</a></li> <li>• <b>Comfort Position</b> - <a href="https://www.chop.edu/centers-programs/child-life-education-and-creative-arts-therapy/prepare-your-child-visit-doctor/comfort-positioning-during-procedures">https://www.chop.edu/centers-programs/child-life-education-and-creative-arts-therapy/prepare-your-child-visit-doctor/comfort-positioning-during-procedures</a></li> <li>• <b>One Voice</b></li> <li>• <b>Cellie Coping Kit (youth)</b> - <a href="https://www.chop.edu/health-resources/cellie-cancer-coping-kit">https://www.chop.edu/health-resources/cellie-cancer-coping-kit</a></li> <li>• <b>Books</b>, for example: <ul style="list-style-type: none"> <li>○ “Imagine What’s Possible” American Cancer Society;</li> <li>○ “Imagine a Rainbow” Brenda Miles;</li> <li>○ “Sitting Still Like a Frog” Eline Snel;</li> <li>○ “Ready, Set, RELAX” Jeffrey Allen and Roger Klein)</li> </ul> </li> </ul> <p><b>Tools to reduce pain and anxiety with injections</b></p> <ul style="list-style-type: none"> <li>• <b>EMLA cream</b> (two topical anesthetics; lidocaine and prilocaine.</li> <li>• <b>AMETOP gel</b> (tetracaine anesthetic)</li> <li>• <b>Buzzy</b> - <a href="https://buzzyhelps.com/">https://buzzyhelps.com/</a></li> <li>• <b>Shot Blocker</b> - <a href="https://www.bionix.com/medicaltech/product/shotblocker/">https://www.bionix.com/medicaltech/product/shotblocker/</a> Drago LA, Singh SB, Doughlass-Bright A, et al. Efficacy of ShotBlocker in reducing pediatric pain associated with intramuscular injections. <i>Am J Emerg Med.</i> 2009;27(5):536-43. <a href="https://www.ncbi.nlm.nih.gov/pubmed/19497458">https://www.ncbi.nlm.nih.gov/pubmed/19497458</a></li> </ul>

Actions	Strategies	Resources/Tools †††
	<ul style="list-style-type: none"> <li>Assess perception of procedure experience with post procedural medical play (especially for toddler/preschoolers) as this play can assist youth with more effective coping for the next procedure and the ability to process the event.</li> <li>If possible or requested by the youth/family, have a team member present at the procedure to provide support, distraction, or other coping interventions. The team member should assess the effectiveness of the preparation interventions and create new plans/support as needed.</li> </ul>	<ul style="list-style-type: none"> <li><b>Freeze Spray</b> - <a href="http://thepainsource.com/painless-injections-%E2%80%93-taking-the-sting-out/">http://thepainsource.com/painless-injections-%E2%80%93-taking-the-sting-out/</a></li> </ul> <p><b>Additional Resources:</b></p> <p>Shockey DP, Menzies V, Glick DF, et al. Preprocedural distress in children with cancer: an intervention using biofeedback and relaxation. <i>J Pediatr Oncol Nurs</i>. 2013;30(3):129–138. doi:10.1177/1043454213479035  <a href="https://pubmed.ncbi.nlm.nih.gov/23542082/?from_term=procedural+distress+in+children+with+cancer+an+intervention+using+biofeedback+and+relaxation&amp;from_pos=1">https://pubmed.ncbi.nlm.nih.gov/23542082/?from_term=procedural+distress+in+children+with+cancer+an+intervention+using+biofeedback+and+relaxation&amp;from_pos=1</a></p> <p>Birnie KA, Kulandaivelu Y, Jibb L, et al. Usability testing of an interactive virtual reality distraction intervention to reduce procedural pain in children and adolescents with cancer. <i>J Pediatr Oncol Nurs</i>. 2018;35(6):406–416. doi:10.1177/1043454218782138  <a href="https://pubmed.ncbi.nlm.nih.gov/29950139/?from_term=interactive+virtual+reality+to+reduce+procedural+pain+in+children+&amp;from_pos=1">https://pubmed.ncbi.nlm.nih.gov/29950139/?from_term=interactive+virtual+reality+to+reduce+procedural+pain+in+children+&amp;from_pos=1</a></p> <p>McGrath P, Huff N. ‘What is it?’ Findings on preschoolers’ responses to play with medical equipment. <i>Child</i>. 2008;27(5):451-462.  <a href="https://doi.org/10.1046/j.1365-2214.2001.00219.x">https://doi.org/10.1046/j.1365-2214.2001.00219.x</a></p> <p>Loeffen EAJ, Mulder RL, Font-Gonzales A, et al. Reducing pain and distress related to needle procedures in children with cancer: A clinical practice guideline. <i>Eur J Cancer</i>. 2020; 131:53-67.  <a href="https://pubmed.ncbi.nlm.nih.gov/32302949/">https://pubmed.ncbi.nlm.nih.gov/32302949/</a></p>

**Standard 9:**

Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship.

Actions	Strategies	Resources/Tools †††
<p><b>9a. Assess current social interaction.</b></p>	<p><b>Identify psychosocial providers who will conduct screening and assessment.</b></p> <ul style="list-style-type: none"> <li>• Assess current social interaction and need for interaction with peers in the community (school absence, contact with peers; quality of peer interactions).</li> <li>• Assess current functioning, needs and preferences regarding general social interaction and social interaction with peers with cancer.</li> <li>• Consider seeking additional information from school personnel and community providers (with permission).</li> </ul> <p><b>Identify appropriate assessment measures.</b></p> <ul style="list-style-type: none"> <li>• Standard assessments with psychometric support and norms.</li> </ul> <p><b>Determine timetable of sequential assessment during and after treatment.</b></p> <ul style="list-style-type: none"> <li>• The youth, caregiver(s), and a psychosocial team member (e.g., designee from child life, psychology,</li> </ul>	<p>Initial assessment and subsequent assessments by nursing, social work, child life and/or psychologist, allowing both the youth and caregiver(s) to provide information.</p> <p>In addition to interview, examples of validated measures include:</p> <ul style="list-style-type: none"> <li>• <b>Behavior Assessment System for Children Third Edition (BASC-3) Adaptive Behavior Subscales</b> Measures – Parent proxy, teacher and self report forms <a href="http://www.Pearsonassessments.com">www.Pearsonassessments.com</a></li> <li>• <b>Child Behavior Checklist (CBCL) Social adaptation</b> Measures – Parent proxy, teacher and self report forms – <a href="http://www.ASEBA.org">www.ASEBA.org</a></li> <li>• <b>Neuro-QOL Pediatric Social Relations</b> – Measures- Child and parent proxy measures of Social Relationships – <a href="http://www.HealthMeasures.net">www.HealthMeasures.net</a></li> <li>• <b>NIH Toolbox Friendships Measures</b> (Child and Parent Proxy) – <a href="http://www.HealthMeasures.net">www.HealthMeasures.net</a></li> <li>• <b>Patient-Reported Outcomes Measurement Information System (PROMIS) Peer Relationships.</b> Measures- Child and parent proxy measures of Peer Relationships – <a href="http://www.HealthMeasures.net">www.HealthMeasures.net</a></li> <li>• <b>PedsQL Social functioning</b> – Measures – Child and Parent Proxy – <a href="http://www.Pedsqil.org">www.Pedsqil.org</a></li> <li>• <b>Observation by team members</b></li> </ul>

Actions	Strategies	Resources/Tools †††
	<p>social work, or nursing) should participate in this evaluation at time of diagnosis, throughout treatment and when the youth enters survivorship.</p> <ul style="list-style-type: none"> <li>• Consider completing assessments at transitional timepoints for school (e.g., entering middle or high school, entering college, etc.) and transitional timepoints for treatment (e.g., diagnosis, change in the phase of treatment, treatment completion, etc.).</li> </ul> <p><b>Establish procedures to incorporate assessment results in treatment planning.</b></p> <ul style="list-style-type: none"> <li>• Information relevant to the assessment question will be shared with staff directly involved in the youth’s care and in person with caregivers. Procedure will balance information sharing with need for confidentiality, e.g., charting procedures, meetings and rounds.</li> <li>• Share assessment and plan with school personnel and community providers (with permission).</li> </ul>	
<p><b>9b. Promote social interaction.</b></p>	<p><b>Promote opportunities for social interactions with consideration for:</b> the youth’s unique characteristics, underlying diagnosis and how social interaction needs</p>	<p><i>*Note: New interventions may be in development, but research reports have yet to be published. Resources below are often used and may be helpful but many have no or limited empirical</i></p>

Actions	Strategies	Resources/Tools †††
	<p>and experiences may vary, isolation precaution requirements and how they impact options and whether treatment is primarily inpatient vs outpatient.</p> <p><b>Hospital-based strategies</b></p> <ul style="list-style-type: none"> <li>• Provide education to youth and families regarding the importance of resuming social interaction when medically able.</li> <li>• Offer inpatient or clinic patient groups.</li> <li>• Connect youth with peer mentors through community programs (e.g., Imerman’s Angels) or via an established hospital-based program.</li> <li>• Create pediatric /adolescent survivor advisory committees to provide input on hospital spaces, hospital policies and activities that promote social development goals.</li> </ul> <p><b>Community-based strategies</b></p> <ul style="list-style-type: none"> <li>• Refer to camps/activity programs.</li> <li>• Provide guidance and where appropriate, facilitate youth connections to peer group throughout treatment (e.g.,</li> </ul>	<p><i>support. In addition, some currently available resources may change over time.</i></p> <ul style="list-style-type: none"> <li>• <b>2bMe</b> - <a href="http://lookgoodfeelbetter.org/2bMe/2bMe.html">http://lookgoodfeelbetter.org/2bMe/2bMe.html</a></li> <li>• <b>13Thirty Cancer Connect</b> - <a href="http://13thirty.org/">http://13thirty.org/</a></li> <li>• <b>AYA Cancer Chat: Life Interrupted Podcasts</b> - <a href="https://www.chop.edu/health-resources/aya-cancer-chat-life-interrupted">https://www.chop.edu/health-resources/aya-cancer-chat-life-interrupted</a></li> <li>• <b>Cancer Care for Kids</b> - <a href="http://www.cancercare.org">www.cancercare.org</a></li> <li>• <b>Cancer Support Community</b> - <a href="http://www.cancersupportcommunity.org">www.cancersupportcommunity.org</a></li> <li>• <b>Children’s Brain Tumor Foundation Signature Programs</b> - <a href="http://cbtf.org/signature-programs/">http://cbtf.org/signature-programs/</a></li> <li>• <b>Children’s Oncology Camping Association-International</b> - <a href="http://www.cocai.org">www.cocai.org</a></li> <li>• <b>First Descents</b> - <a href="https://firstdescents.org/">https://firstdescents.org/</a></li> <li>• <b>Imerman Angels</b> - <a href="http://imermanangels.org/">http://imermanangels.org/</a></li> <li>• <b>Leukemia/Lymphoma Society Online Chats</b> - <a href="https://www.lls.org/support/online-chats">https://www.lls.org/support/online-chats</a></li> <li>• <b>LiveStrong Guide to Connecting with Others Like You</b> - <a href="https://www.livestrong.org/we-can-help/preparing-yourself/meeting-others-like-you">https://www.livestrong.org/we-can-help/preparing-yourself/meeting-others-like-you</a></li> <li>• <b>Stupid Cancer Young Adult Support Resources</b> - <a href="http://stupidcancer.org/directories/yaorgs.shtml">http://stupidcancer.org/directories/yaorgs.shtml</a></li> </ul> <p><b>Additional Resources:</b>  Zadeh S, Tunick R. Social Media Use in Pediatric Oncology. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 339-350.</p>



Actions	Strategies	Resources/Tools †††
	through school, social media, eHealth tools, activities, etc.).	Zadeh S, Golant M, Phillips F, et al. Resources Chapter. In Abrams AN, Muriel AL & Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i> . New York, Springer; 2016: 397-409.

**Standard 10:**

Siblings of youth with cancer should be provided with appropriate supportive services. Parents and professionals should be advised about ways to anticipate and meet siblings’ needs, especially when siblings are unable to visit the hospital regularly.

Actions	Strategies	Resources/Tools †††
<p><b>10a. Assess and address psychosocial needs of siblings.</b></p>	<p><b>Obtain a comprehensive assessment of the psychosocial functioning and needs of siblings</b> prior to the youth's treatment and currently.</p> <ul style="list-style-type: none"> <li>• <b>Assess adjustment, quality of life, sleep, academic and social functioning, quality of family communication, strengths</b> from sibling and parent perspectives preferably in person or via phone/proxy report if needed.</li> <li>• <b>Reassess sibling functioning and needs every 6 months or at key points</b> during and after treatment (e.g., extended hospital stays, relapse, HSCT, palliative care) if not sooner.</li> <li>• <b>If the sibling is a donor, assess and address psychosocial needs</b> during preparation, assent process, and after donation.</li> </ul>	<p><b>Assessments by nursing, social work, child life and/or psychologist</b>, should allow both the sibling and caregiver(s) to provide information. In addition to interview, examples of measures include:</p> <ul style="list-style-type: none"> <li>• <b>Pediatric PROMIS Measures</b> - <a href="http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis">http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis</a></li> <li>• <b>Strengths and Difficulties Questionnaire</b> - <a href="https://depts.washington.edu/dbpeds/Screening%20Tools/Strengths_and_Difficulties_Questionnaire.pdf">https://depts.washington.edu/dbpeds/Screening%20Tools/Strengths_and_Difficulties_Questionnaire.pdf</a></li> <li>• <b>Sibling Cancer Needs Instrument</b></li> <li>• <b>Psychosocial Assessment Tool – Extended Sibling Version</b></li> <li>• <b>Behavior Assessment System for Children</b> - <a href="https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Behavior/Comprehensive/Behavior-Assessment-System-for-Children-%7C-Third-Edition-/p/100001402.html">https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Behavior/Comprehensive/Behavior-Assessment-System-for-Children-%7C-Third-Edition-/p/100001402.html</a></li> <li>• <b>Child Behavior Checklist</b> - <a href="https://aseba.org">https://aseba.org</a></li> <li>• <b>AYA Needs Measures</b> - <a href="http://bit.ly/AYANeedsMeasures">http://bit.ly/AYANeedsMeasures</a></li> </ul>
<p><b>10b. Advise parents and professionals about ways to</b></p>	<ul style="list-style-type: none"> <li>• <b>Provide family-centered care</b> including supportive care of siblings at the center or provide referrals to community-based mental health</li> </ul>	<p><i>*Note: New interventions may be in development, but research reports have yet to be published. Resources below are often used and may be helpful but many have no or limited empirical</i></p>

Actions	Strategies	Resources/Tools †††
<p><b>anticipate and meet siblings' needs, especially when siblings are unable to visit the hospital regularly.</b></p>	<p>providers if needed. Appropriate support services may include psychoeducation, child life services, hospital-based individual or family therapy, support groups, or referral to community programs.</p> <ul style="list-style-type: none"> <li>• <b>Teach effective family communication skills</b> to provide developmentally appropriate information and help siblings to express feelings, questions, and needs.</li> <li>• For siblings staying at home while the youth is hospitalized, <b>assist parents in coordinating daily phone calls or internet communication</b> (e.g., Skype, Facetime) for duration of hospital stay.</li> <li>• <b>Help siblings feel more engaged</b> (for example, draw pictures to hang up in the youth's room, pick pajamas for parents to bring to the hospital).</li> <li>• <b>Introduce the sibling by name to the medical team</b>, when present.</li> <li>• <b>Determine the level of sibling interest in involvement in care</b> and facilitate this when possible (demands for role changes, additional responsibilities at</li> </ul>	<p><i>support. In addition, some currently available resources may change over time.</i></p> <p><b>Additional Resources:</b>  Prchal A, Graf A, Bergstresser E et al. A two-session psychological intervention for siblings of pediatric cancer patients: a randomized controlled pilot trial. <i>Child Adolesc Psychiatry Ment Health</i>. 2012;6(1):3. Published 2012 Jan 11. doi:10.1186/1753-2000-6-3  <a href="https://www.ncbi.nlm.nih.gov/pubmed/?term=landolt+psychosocial+intervention+for+siblings">https://www.ncbi.nlm.nih.gov/pubmed/?term=landolt+psychosocial+intervention+for+siblings</a></p> <p><b>Informational resources for education and family-centered care include:</b></p> <ul style="list-style-type: none"> <li>• <b>National Cancer Institute booklet for siblings</b> - <a href="https://www.cancer.gov/publications/patient-education/sibling-has-cancer">https://www.cancer.gov/publications/patient-education/sibling-has-cancer</a></li> <li>• <b>National Cancer Institute, Center for Cancer Research therapeutic workbooks and booklets for siblings and stem cell donors</b> - <a href="https://ccr.cancer.gov/Pediatric-Oncology-Branch/psychosocial/education">https://ccr.cancer.gov/Pediatric-Oncology-Branch/psychosocial/education</a></li> <li>• <b>Children's Cancer Web support resources and research for siblings of youth with cancer</b> - <a href="http://www.cancerindex.org/ccw/siblings#section1">http://www.cancerindex.org/ccw/siblings#section1</a></li> <li>• <b>Books for siblings of children with special needs</b> - <a href="https://siblingssupport.org/publications/landing-page">https://siblingssupport.org/publications/landing-page</a></li> <li>• <b>SuperSibs Programs for siblings of youth with cancer</b> - <a href="https://www.alexslimonade.org/campaign/supersibs-sibling-support-childhood-cancer-families">https://www.alexslimonade.org/campaign/supersibs-sibling-support-childhood-cancer-families</a></li> </ul>

Actions	Strategies	Resources/Tools †††
	<p>home, diminished contact with parents and their ill sibling).</p> <ul style="list-style-type: none"> <li>• <b>With parent permission, notify school personnel</b> (teachers, social workers and psychologists, guidance counselor) to ensure in-school support for siblings if needed.</li> <li>• <b>Collaborate with parents, extended family, and professionals</b> to address sibling needs on an ongoing basis.</li> <li>• <b>Offer opportunities for siblings to connect with other siblings</b> of youth by providing referrals to support groups and family or sibling support camps, if available at center or in community.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>CanTeen offers education and support for siblings of youth with cancer</b> - <a href="https://www.canteen.org.au/about-us/the-need-for-support/siblings/">https://www.canteen.org.au/about-us/the-need-for-support/siblings/</a></li> </ul> <p><b>Resources for helping families, school personnel, and other professionals support siblings:</b></p> <ul style="list-style-type: none"> <li>• <b>American Cancer Society tips for helping siblings of youth with cancer</b> - <a href="https://www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/after-diagnosis/helping-siblings.html">https://www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/after-diagnosis/helping-siblings.html</a></li> <li>• <b>Cancer.net sponsored by the American Society for Clinical Oncology tips on helping siblings</b> - <a href="https://www.cancer.net/blog/2017-05/how-help-healthy-children-cope-when-sibling-has-cancer">https://www.cancer.net/blog/2017-05/how-help-healthy-children-cope-when-sibling-has-cancer</a></li> <li>• <b>CancerCare fact sheet for parents talking to siblings</b> - <a href="https://www.cancercare.org/publications/50-helping-the-siblings-of-the-child-with-cancer">https://www.cancercare.org/publications/50-helping-the-siblings-of-the-child-with-cancer</a></li> <li>• <b>CancerCare information for teachers and educators</b> - <a href="https://www.cancercare.org/connect_workshops/78-cancer_sibling_support_2009-10-08">https://www.cancercare.org/connect_workshops/78-cancer_sibling_support_2009-10-08</a></li> </ul> <p><b>Opportunities to connect with other siblings</b> may include camps or other institutional programs.</p> <ul style="list-style-type: none"> <li>• <b>Sibling camps by state</b> - <a href="https://www.alexslimonade.org/campaign/supersibs-sibling-support-childhood-cancer-families/camps-childhood-cancer-families">https://www.alexslimonade.org/campaign/supersibs-sibling-support-childhood-cancer-families/camps-childhood-cancer-families</a></li> <li>• <b>Children’s Oncology Camping Association International</b> - <a href="http://www.cocai.org">www.cocai.org</a></li> </ul>

Actions	Strategies	Resources/Tools †††
		<ul style="list-style-type: none"> <li>• <b>The Sibling Support Project and Sibshops peer support programs for siblings of youth with special needs</b> - <a href="https://siblingsupport.org/">https://siblingsupport.org/</a></li> </ul>
<p><b>10c. Inform and educate staff about sibling psychosocial needs.</b></p>	<p><b>Provide training about the impact of cancer on siblings</b>, their needs, and effective care.</p> <p><b>Provide information on community resources</b> to all staff caring for youth and their siblings.</p> <p><b>Increase accessibility of healthcare providers to siblings</b> and promote sibling-provider communication.</p> <p><b>Identify a member of the psychosocial team to monitor and respond to sibling needs.</b></p>	<p><b>Training and community resources may include:</b></p> <ul style="list-style-type: none"> <li>• <b>Sibling Voices video to educate others about the sibling experience</b> - <a href="https://www.dana-farber.org/for-patients-and-families/care-and-treatment/support-services-and-amenities/sibling-program/">https://www.dana-farber.org/for-patients-and-families/care-and-treatment/support-services-and-amenities/sibling-program/</a></li> <li>• <b>CancerCare information for parents and professionals who are helping siblings</b> - <a href="https://www.cancercare.org/connect_workshops/96-cancer_siblings_2009-05-14">https://www.cancercare.org/connect_workshops/96-cancer_siblings_2009-05-14</a></li> <li>• <b>ShopTalk</b>, a therapeutic game designed to help professionals have conversations with siblings about difficult emotions and cancer - <a href="https://ccr.cancer.gov/Pediatric-Oncology-Branch/psychosocial/education">https://ccr.cancer.gov/Pediatric-Oncology-Branch/psychosocial/education</a></li> </ul> <p><b>Additional Reading Material:</b></p> <p>Kazak AK, DiDonato S, Schneider S, et al. Assessing Family Psychosocial Risks in Pediatric Cancer. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 51-66.</p> <p>Zadeh S, Golant M, Phillips F, et al. Resources Chapter. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 397-409.</p>

**Standard 11:**

Academic Continuity and School Reentry Support as a Standard of Care in Pediatric Oncology. Strategies for Program Development and Improvement

Actions	Strategies	Resources †††
<p><b>11a. In collaboration with parents, provide school reentry support for school-age youth diagnosed with cancer that focuses on providing information to school personnel about the youth’s diagnosis, treatment, and implications for the school environment and provides recommendations to support the youth’s school experience.</b></p>	<p><b>Coordinate with the medical team</b> to understand the implications of the specific disease and treatment on school attendance, cognition, etc.</p> <p><b>Educate Youth and Parents Regarding:</b></p> <ul style="list-style-type: none"> <li>• Short and long-term impact of disease and treatment on school attendance and performance</li> <li>• Strategies to mitigate negative experiences or challenging circumstances related to school or attainment</li> <li>• Importance of school-family communication</li> <li>• Educational rights and resources</li> <li>• Information about educational opportunities (scholarship or tutoring resources)</li> </ul> <p><b>Utilize risk-based education assessment</b> (e.g., Elam, Murphy, &amp; Irwin) to guide tiered support provided by the liaison.</p> <p><b>Tailor educational support</b> to the youth’s specific disease, treatment and associated</p>	<p><i>*Note: New interventions may be in development, but research reports have yet to be published. Resources below are often used and may be helpful but currently have limited empirical support. In addition, some currently available resources may change over time.</i></p> <p><b>Assessment/Intervention:</b>            Elam, M, Murphy, C, Irwin, MK. Validity, reliability, and feasibility of the Brief School Needs Inventory: Evaluating educational risk for students with chronic health conditions. <i>Psycho-Oncology</i>. 2019; 28: 1483– 1489.  <a href="https://onlinelibrary.wiley.com/doi/full/10.1002/pon.5104">https://onlinelibrary.wiley.com/doi/full/10.1002/pon.5104</a></p> <p><b>Books for Parents and Teachers:</b></p> <ul style="list-style-type: none"> <li>• Hoffman R.I. (Ed). <i>Educating the child with cancer: A guide for parents and teachers, 2<sup>nd</sup> Ed.</i> Kensington, MD: American Childhood Cancer Organization; 2013.  <a href="http://www.acco.org">www.acco.org</a></li> <li>• <i>Taking Cancer to School</i> by Kim Gosselin</li> </ul> <p><b>Classroom Resources:</b></p> <ul style="list-style-type: none"> <li>• <b>CancerEd</b> - <a href="http://www.CancerEd.org">www.CancerEd.org</a></li> <li>• <b>HopeCam</b> - <a href="https://www.hopecam.org/">https://www.hopecam.org/</a></li> <li>• <b>Monkey In My Chair</b> - <a href="http://www.monkeyinmychair.org/">http://www.monkeyinmychair.org/</a></li> </ul>

Actions	Strategies	Resources †††
	<p>issues. This may need to occur several times over the course of treatment and post treatment, as the youth transitions between schools and/or phases of treatment and survivorship. Attention to post-secondary transitions (e.g., college, vocational rehab) for AYAs will be important.</p> <p><b>Obtain consent to contact and share information with relevant school personnel.</b></p> <p><b>Provide information, education, and resources to school</b> via school letter, phone call/conference, video conference, and/or in-person visit re:</p> <ul style="list-style-type: none"> <li>• Youth’s diagnosis and treatment plan</li> <li>• Implications for school setting/academic progress</li> <li>• Suggestions for discussing youth’s absence and/or return to school with classmates</li> <li>• Recommendations for school accommodations</li> </ul> <p><b>Facilitate alternative educational arrangements</b> when a student is unable to attend school. Explore feasibility, processes and procedures of options such as returning part time, receiving homebound instruction,</p>	<p><b>Return to School – Information for Child with Cancer, Their Families, and School Staff Members:</b></p> <ul style="list-style-type: none"> <li>• <b>Alex’s Lemonade Stand Foundation</b>, School Guide: Supporting Families and Classmates Affected by Childhood Cancer - <a href="https://www.alexlemonade.org/sites/default/files/school_guide_layout1_final.pdf">https://www.alexlemonade.org/sites/default/files/school_guide_layout1_final.pdf</a></li> <li>• <b>American Cancer Society</b>, Helping Your Child Manage School During Cancer Treatment - <a href="https://www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/during-treatment/keeping-up-with-schoolwork.html">https://www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/during-treatment/keeping-up-with-schoolwork.html</a></li> <li>• <b>American Cancer Society</b>, Returning to School After Cancer Treatment - <a href="https://www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/after-treatment/returning-to-school.html">https://www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/after-treatment/returning-to-school.html</a></li> <li>• <b>Leukemia &amp; Lymphoma Society</b>, School - <a href="https://www.lls.org/childhood-blood-cancer/about-childhood-blood-cancer/school">https://www.lls.org/childhood-blood-cancer/about-childhood-blood-cancer/school</a></li> <li>• <b>Livestrong at School</b> - Academic Standards, Lessons, and Activities for Grades K-12 - <a href="http://www.scholastic.com/livestrong/">http://www.scholastic.com/livestrong/</a></li> </ul>

Actions	Strategies	Resources †††
	<p>or other alternative technology educational options (e.g., linking to the school via remote online systems) or a combination of several arrangements.</p> <p><b>Prepare teachers, students, youth, and parents</b>, by providing resources and support for school re-entry, peer education, and ongoing school supports. Classroom teachers may benefit from discussion regarding how other students may respond toward the youth with cancer (e.g., questions classmates might ask about the returning student's health, changes in appearance, etc.) and ideas to maintain engagement between the school community and the student while the student is away from the classroom.</p> <p><b>In collaboration with the family and medical team:</b></p> <ul style="list-style-type: none"> <li>• Assess readiness for school re-entry</li> <li>• Provide appropriate supports and assist with re-entry plan</li> <li>• Guide the development of appropriate educational assessments and documents (e.g., IEP, 504 Plan, IHP, SSP, etc.)</li> <li>• Provide ongoing supports and resources as appropriate and needed</li> </ul>	<p><b>Post-Secondary Education or Work:</b></p> <ul style="list-style-type: none"> <li>• <b>Cancer.Net</b>, Returning to School or Work After Cancer <a href="https://www.cancer.net/navigating-cancer-care/young-adults/returning-school-or-work-after-cancer">https://www.cancer.net/navigating-cancer-care/young-adults/returning-school-or-work-after-cancer</a></li> <li>• <b>Cancer and Careers</b> - <a href="https://www.cancerandcareers.org/">https://www.cancerandcareers.org/</a></li> <li>• <b>Scholarships for Cancer Survivors</b> - <a href="http://ped-onc.org/scholarships/index.html">http://ped-onc.org/scholarships/index.html</a></li> </ul> <p><b>Websites and Organizations:</b></p> <ul style="list-style-type: none"> <li>• <b>Wright's Law</b> - <a href="http://www.wrightslaw.com">www.wrightslaw.com</a> <i>Information about special education law and advocacy</i></li> </ul>



Actions	Strategies	Resources †††
	<ul style="list-style-type: none"> <li>• Facilitate referral for psychoeducational and/or neuropsychological evaluation as indicated</li> <li>• Collaborate with psychology or neuropsychology to monitor for emergence of cognitive late-effects of treatment</li> </ul> <p><b>Document activity in the electronic medical record</b> to facilitate communication with other team members and to provide evidence of support and outcomes.</p>	
<p><b>11b. Pediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the youth/ family, school, and the health care team.</b></p>	<p><b>Designate a School Liaison:</b></p> <ul style="list-style-type: none"> <li>• Member of the healthcare or psychosocial team who has or will develop expertise around educational impact of cancer</li> <li>• Knowledgeable about state and federal education laws, state standards and regulations, and common practices within the education system</li> <li>• Knowledgeable about local community resources for educational advocacy, post-secondary transition services (and scholarship opportunities), and organizations that have programs and</li> </ul>	<p><b>Educational Law:</b></p> <ul style="list-style-type: none"> <li>• <b>State Department of Education</b></li> <li>• <b>U.S. Department of Education. Office of Special Education and Rehabilitative Services</b>  <a href="https://www2.ed.gov/about/offices/list/osers/osep/index.htm">https://www2.ed.gov/about/offices/list/osers/osep/index.htm</a>  <u>1</u></li> <li>• <b>Wrightslaw Yellow Pages for Kids</b>  <a href="http://www.yellowpagesforkids.com">www.yellowpagesforkids.com</a></li> </ul> <p><b>Disability Resources:</b></p> <ul style="list-style-type: none"> <li>• <b>Local Board of Developmental Disabilities</b></li> <li>• <b>Office of Civil Rights</b></li> <li>• <b>State Department of Rehabilitation</b></li> <li>• <b>U.S. Department of Education. Office of Special Education and Rehabilitative Services</b>  <a href="https://www2.ed.gov/about/offices/list/osers/osep/index.htm">https://www2.ed.gov/about/offices/list/osers/osep/index.htm</a>  <u>1</u></li> </ul>

Actions	Strategies	Resources †††
	<p>services to support the psychosocial needs of the youth and family</p> <ul style="list-style-type: none"> <li>• Acts as a liaison and advocate between family, school, and the health care team to coordinate school supports</li> <li>• Follows the school-age youth throughout the course of treatment and into survivorship</li> <li>• Tailors supports to the needs of the student as they move through treatment and school transitions</li> <li>• Has experience in developmentally appropriate delivery of instruction to ensure: <ul style="list-style-type: none"> <li>○ Effectiveness of peer education programming</li> <li>○ Educational recommendations for school supports are developmentally appropriate</li> </ul> </li> <li>• Possesses strong communication, relationship management, and advocacy skills</li> <li>• Maintains up-to-date knowledge of educational trends</li> </ul>	<p><b>Hospital Program Resources</b></p> <ul style="list-style-type: none"> <li>• <b>APHOES Practice Recommendations</b>  <a href="https://www.healassociation.org/wp-content/uploads/2019/03/APHOES-Practice-Recommendations-No-Password-Book-Baby-Revised-Version2015-1.pdf">https://www.healassociation.org/wp-content/uploads/2019/03/APHOES-Practice-Recommendations-No-Password-Book-Baby-Revised-Version2015-1.pdf</a> (temporary location)</li> <li>• <b>Hospital Educator and Academic Liaison Association (HEAL)</b> website section “Guidelines for Building a Hospital School Program” (NOTE: this section is members only)</li> </ul> <p><b>Professional Organizations:</b></p> <ul style="list-style-type: none"> <li>• <b>HEAL: Health Educator and Academic Liaison Association</b> - <a href="https://www.healassociation.org/">https://www.healassociation.org/</a></li> <li>• <b>CEC: Council for Exceptional Children</b> - <a href="https://www.cec.sped.org/">https://www.cec.sped.org/</a></li> </ul> <p><b>Online Education Modules (CEUs available):</b></p> <ul style="list-style-type: none"> <li>• <b>Staying Connected: Facilitating the Learning Experience During and After Cancer Treatment</b>  <a href="https://www.lls.org/professional-education-webcasts/staying-connected-facilitating-the-learning-experience-during-and-after-cancer-treatment">https://www.lls.org/professional-education-webcasts/staying-connected-facilitating-the-learning-experience-during-and-after-cancer-treatment</a></li> </ul> <p><b>Additional Reading Material:</b>  Trask CL, Peterson CC. Educational issues: The impact of cancer in the classroom. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 175-198.</p>

Actions	Strategies	Resources †††
	<ul style="list-style-type: none"> <li>• Understands disease process and treatment protocol in terms of impact on school participation and achievement</li> <li>• Provides education related guidance and consultation to the medical and psychosocial team members</li> </ul>	

**Standard 12:**

Assessing Medication Adherence as a Standard of Care in Pediatric Oncology. Adherence should be assessed routinely and monitored throughout the treatment.

Actions	Strategies	Resources †††
<p><b>12a. Assess medication adherence.</b></p>	<p><b>Provide education to the clinical team</b> on the prevalence, impact, and potential facilitators/ barriers of adherence.</p> <p><b>Identify the team members responsible</b> for assessment of adherence, facilitators/barriers, and documentation.</p> <p><b>Identify an evidence-based adherence assessment strategy</b> that aligns with clinical resources.</p> <p><b>Identify an evidence-based facilitators/ barriers assessment strategy</b> that aligns with clinical resources.</p> <p><b>Create a standardized documentation strategy</b> to track adherence and facilitators/barriers.</p>	<p><b>Education:</b></p> <ul style="list-style-type: none"> <li>• <b>Fact sheet on adherence</b> - <a href="https://www.societyofpediatricpsychology.org/medical_regimens">https://www.societyofpediatricpsychology.org/medical_regimens</a></li> </ul> <p><b>Assessment:</b></p> <ul style="list-style-type: none"> <li>• <b>Evidence Based Measures of Adherence</b> - <a href="https://www.societyofpediatricpsychology.org/measures_of_adherence">https://www.societyofpediatricpsychology.org/measures_of_adherence</a></li> <li>• <b>Adherence assessment</b> may include caregiver or youth report, standardized check-lists or questionnaires, pill counts, pharmacy records, medication blood levels (when validated), electronic pill bottles or boxes.</li> <li>• <b>Evidence-Based Barriers Assessment</b> Plevinsky JM, Gutierrez-Colina A, Carmody JK, et al. Patient-reported outcomes for pediatric adherence and self-management: A systematic review. <i>Journal of Pediatric Psychol.</i> 2020;45(3):340-357. <a href="https://academic.oup.com/jpepsy/article-abstract/45/3/340/5679921?redirectedFrom=fulltext">https://academic.oup.com/jpepsy/article-abstract/45/3/340/5679921?redirectedFrom=fulltext</a></li> </ul> <p><b>Documentation:</b></p> <ul style="list-style-type: none"> <li>• Use electronic health record tools (e.g., EPIC smart phrases, tablets, documentation flow sheets)</li> </ul>
<p><b>12b. Provide nonadherence interventional support to youth and family.</b></p>	<p><b>Identify the team members responsible</b> for identifying youth requiring interventions, facilitating necessary referrals, and delivering interventions.</p>	<p><b>Adherence Education:</b></p> <ul style="list-style-type: none"> <li>• <b>Center for Adherence and Self Management</b> - <a href="https://www.cincinnatichildrens.org/research/divisions/c/adherence">https://www.cincinnatichildrens.org/research/divisions/c/adherence</a></li> <li>• <b>American Medical Association Education Hub</b> –</li> </ul>

Actions	Strategies	Resources †††
	<p><b>Provide education regarding the medication regimen</b> including the purpose, administration, and side effects of each medication.</p> <p><b>Provide education regarding medication adherence</b> including the prevalence of non-adherence, importance of adherence, and potential impact of barriers on adherence.</p> <p><b>Provide targeted evidence-based interventions to address identified barriers</b> to adherence. Examples below:</p> <p><b>Barriers:</b> Financial/logistical causes (e.g., lack of financial resources, lack of transportation):</p> <ul style="list-style-type: none"> <li>• Connect the family with local resources (e.g., foundations to provide transportation, pay bills, medication delivery services)</li> <li>• Address the stressors that likely result from these strains (e.g., therapy).</li> </ul> <p>Lack of health knowledge/ understanding (e.g., when or how to take medication):</p> <ul style="list-style-type: none"> <li>• Provide culturally-sensitive education regarding the importance of maintaining a medication routine</li> <li>• Utilize medical language translators as needed</li> </ul>	<p><a href="https://edhub.ama-assn.org/steps-forward/module/2702595">https://edhub.ama-assn.org/steps-forward/module/2702595</a></p> <p><b>Adherence Reminders:</b></p> <ul style="list-style-type: none"> <li>• There are many medication tracking applications available. There are many available and there are articles to help providers choose what will align best with their practice</li> <li>• Santo K, Richtering SS, Chalmers J, et al. Mobile Phone Apps to Improve Medication Adherence: A Systematic Stepwise Process to Identify High-Quality Apps. <i>JMIR Mhealth Uhealth</i>. 2016;4(4):e132. Published 2016 Dec 2. doi:10.2196/mhealth.6742 <a href="https://pubmed.ncbi.nlm.nih.gov/27913373/">https://pubmed.ncbi.nlm.nih.gov/27913373/</a></li> <li>• Ahmed I, Ahmad NS, Ali S, et al. Medication Adherence Apps: Review and Content Analysis. <i>JMIR Mhealth Uhealth</i>. 2018;6(3):e62. Published 2018 Mar 16. doi:10.2196/mhealth.6432 <a href="https://www.ncbi.nlm.nih.gov/pubmed/29549075">https://www.ncbi.nlm.nih.gov/pubmed/29549075</a></li> </ul> <p><b>Adherence Interventions:</b> Adherence interventions vary based on individual barriers. There are articles to assist providers in matching interventions to an individual's barriers.</p> <ul style="list-style-type: none"> <li>• Allemann SS, Nieuwlaat R, van den Bemt BJ, Hersberger KE, Arnet I. Matching adherence interventions to patient determinants using the theoretical domains framework. <i>Frontiers in pharmacology</i>. 2016;7:429. <a href="https://www.frontiersin.org/articles/10.3389/fphar.2016.00429/full">https://www.frontiersin.org/articles/10.3389/fphar.2016.00429/full</a></li> <li>• McGrady ME, Ryan JL, Brown GA, et al. Topical Review: Theoretical Frameworks in Pediatric Adherence-Promotion Interventions: Research Findings and Methodological</li> </ul>

Actions	Strategies	Resources †††
	<ul style="list-style-type: none"> <li>• Provide tools or written instructions/diagrams to simplify the process of taking medication.</li> </ul> <p>Forgetting to take medications:</p> <ul style="list-style-type: none"> <li>• Problem-solving to identify reminder strategies that align with youth preferences (e.g., calendars, text message reminders, etc.).</li> </ul> <p>When no specific barrier identified: Provide interdisciplinary support that addresses potential youth and family factors (e.g., cognitive behavioral therapy, family therapy, financial resources, etc.).</p>	<p>Implications. <i>J Pediatr Psychol.</i> 2015;40(8):721-6.  <a href="https://academic.oup.com/jpepsy/article/40/8/721/929110">https://academic.oup.com/jpepsy/article/40/8/721/929110</a></p> <ul style="list-style-type: none"> <li>• Coyne KD, Trimble KA, Lloyd A, et al. Interventions to Promote Oral Medication Adherence in the Pediatric Chronic Illness Population: A Systematic Review From the Children’s Oncology Group. <i>J Pediatr Oncol Nurs.</i> 2019;36(3):219-35.  <a href="https://journals.sagepub.com/doi/abs/10.1177/1043454219835451">https://journals.sagepub.com/doi/abs/10.1177/1043454219835451</a></li> </ul> <p><b>Additional Reading Material:</b></p> <p>Pai, A. L. H. &amp; Drotar, D (2015). Medication Adherence in Pediatric Oncology. In L. S. Wiener, M. Pao, A. E. Kazak, M. Kupst, A. F. Patenaude, &amp; J. C. Holland (Eds.). <i>Quick Reference for Pediatric Oncology Clinicians: The Psychiatric and Psychological Dimensions</i></p> <p>Mullins LL, Tackett, AP, Suorsa, KI. Psychotherapeutic Modalities for Children. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care.</i> New York, Springer; 2016: 81-106.</p> <p>Zebrack B, Judge Santacroce S. Adolescents and young adults with cancer. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care.</i> New York, Springer; 2016: 199-218.</p> <p>Karlson CW, Palermo TM. eHealth and mHealth in pediatric oncology. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care.</i> New York, Springer; 2016: 351-366.</p>

**Standard 13:**

Palliative Care as a Standard of Care in Pediatric Oncology

Actions	Strategies	Resources/Tools †††
<p><b>13a. Introduce youth with cancer and their families to palliative care concepts to reduce suffering (physical, social emotional, spiritual) throughout the disease process regardless of disease status.</b></p>	<p><b>Educate oncology team members on palliative care concepts to ensure concurrent primary palliative care for all youth as part of quality oncology care.</b></p> <ul style="list-style-type: none"> <li>Primary palliative care concepts include symptom assessment and intervention, direct youth report of symptoms, effective communication, and shared decision making.</li> </ul> <p><b>Identify and equip specialty-trained palliative care team members and/or embedded oncology team members designated as palliative care specialists based on interest or formal training.</b></p> <ul style="list-style-type: none"> <li>Develop a triage approach for all youth to receive concurrent primary palliative care at diagnosis and longitudinally while higher-risk youth then also receive early integration of specialist interdisciplinary palliative care (inclusive of medicine, nursing, chaplaincy, social work, and child life).</li> </ul> <p><b>Offer developmentally-tailored information and resources for youth and their family about the diagnoses and prognosis, symptom management,</b></p>	<p><b>Online Resources:</b></p> <ul style="list-style-type: none"> <li><b>Center to Advance Palliative Care (CAPC)</b> <a href="https://www.capc.org/toolkits/designing-a-pediatric-palliative-care-program/">https://www.capc.org/toolkits/designing-a-pediatric-palliative-care-program/</a></li> <li><b>National Hospice and Palliative Care Organization (NHPCO)</b> <a href="https://www.nhpc.org/pediatrics">https://www.nhpc.org/pediatrics</a></li> <li><b>Courageous Parents Network (CPN)</b> <a href="https://courageousparentsnetwork.org/">https://courageousparentsnetwork.org/</a></li> </ul> <p><b>Helpful Handouts:</b></p> <ul style="list-style-type: none"> <li><b>Palliative Care for Children</b> <a href="https://www.ninr.nih.gov">in English</a> and <a href="https://www.ninr.nih.gov">in Spanish</a></li> </ul> <p><b>Training Resources:</b></p> <ul style="list-style-type: none"> <li><b>International Children’s Palliative Care Network (ICPCN) E-Learning Programme</b> <a href="http://www.icpcn.org/icpcns-elearning-programme/">http://www.icpcn.org/icpcns-elearning-programme/</a></li> <li><b>Pediatric-ELNEC (End-of-Life Nursing Education Consortium)</b> <a href="https://www.aacnnursing.org/ELNEC">https://www.aacnnursing.org/ELNEC</a></li> <li><b>Pediatric-EPEC (Education in Palliative and End-of-Life Care)</b> <a href="https://www.bioethics.northwestern.edu/programs/epec/curricula/pediatrics.html">https://www.bioethics.northwestern.edu/programs/epec/curricula/pediatrics.html</a></li> </ul> <p><b>Standards for Pediatric Palliative Care Resources:</b></p> <ul style="list-style-type: none"> <li><b>Center to Advance Palliative Care (CAPC)</b> criteria – recommendations for early consultation for Palliative Care:</li> </ul>

Actions	Strategies	Resources/Tools †††
	<p>supportive care, and available psychosocial resources (Standard 8).</p> <p><b>Routinely obtain and document patient-reported outcomes (PROs)</b> for symptom assessment and intervention.</p> <p><b>Involve parents/ caregivers and youth/AYA in ongoing treatment discussions, including end of life discussions</b> (i.e., conversations about prognosis, treatment options, decision-making, youth goals, goals of treatment and care, grief, spirituality/existential struggles, legacy, etc.).</p> <p><b>The youth’s opinion about care should be sought as developmentally able to do so.</b></p> <p><b>Use standardized advance care planning (ACP) tools</b> to facilitate early discussions with youth and families about goals of care.</p> <p><b>Collaborate closely with community-based palliative and hospice providers</b> to honor family preference for location of end of life care and to ensure ongoing symptom management.</p> <p><b>Implement standardized family bereavement care regardless of location of death.</b></p>	<p><a href="https://www.capc.org/">https://www.capc.org/</a></p> <ul style="list-style-type: none"> <li>Refer to <b>National Hospice and Palliative Care Organization</b> for Standards of Pediatric Palliative care and other resources:  <a href="https://www.nhpco.org/palliative-care-overview/pediatric-palliative-and-hospice-care/pediatrics-professional-resources/">https://www.nhpco.org/palliative-care-overview/pediatric-palliative-and-hospice-care/pediatrics-professional-resources/</a></li> </ul> <p><b>Book References:</b></p> <ul style="list-style-type: none"> <li>Wolfe J, Jones BL, Kreicbergs U, Momcilo J. Palliative Care in Pediatric Oncology. New York: Springer; 2018.</li> <li>Wolfe J, Hinds PS, Barbara Sourkes B. Textbook of Interdisciplinary Pediatric Palliative Care. Philadelphia: Saunders; 2020.</li> </ul> <p><b>Talking about feelings with children experiencing serious illness</b>  <a href="https://www.maginationpressfamily.org/stress-anxiety-in-kids/talking-about-feelings-with-children-experiencing-serious-illness/">https://www.maginationpressfamily.org/stress-anxiety-in-kids/talking-about-feelings-with-children-experiencing-serious-illness/</a></p> <p><b>Patient-Reported Outcomes (PRO) Resources:</b></p> <ul style="list-style-type: none"> <li><b>Pediatric PROMIS</b> (<i>Patient-Reported Outcomes Measurement Information System</i>) Measures  <a href="http://www.healthmeasures.net/explore-measurement-systems/promis">http://www.healthmeasures.net/explore-measurement-systems/promis</a></li> <li><b>Pediatric PRO-CTCAE</b> (Patient Reported Outcome - Common Terminology Criteria for Adverse Events)  <a href="https://healthcaredelivery.cancer.gov/pro-ctcae">https://healthcaredelivery.cancer.gov/pro-ctcae</a></li> </ul> <p><b>Global Hospice Resource:</b></p> <ul style="list-style-type: none"> <li><b>EHospice</b></li> </ul>



Actions	Strategies	Resources/Tools †††
		<p><a href="https://ehospice.com/international-childrens/">https://ehospice.com/international-childrens/</a></p> <ul style="list-style-type: none"> <li>• <b>World Health Organization Integrating palliative care for symptom relief into paediatrics</b> <a href="https://apps.who.int/iris/handle/10665/274561">https://apps.who.int/iris/handle/10665/274561</a></li> </ul> <p><b>Palliative Care Communication Training Resources</b> In addition to basic training as above:</p> <ul style="list-style-type: none"> <li>• <b>ELNEC Comfort communication</b> (Training all-inclusive not pediatrics specific. Have pediatric content. ELNEC communication curriculum. <a href="https://www.aacnnursing.org/ELNEC/comfort">https://www.aacnnursing.org/ELNEC/comfort</a></li> <li>• <b>Vital Talk</b> (<a href="https://www.vitaltalk.org/">https://www.vitaltalk.org/</a>) – more provider focused. But can adapt for how to respond.</li> <li>• <b>Conversation Starter Kit</b> – available online (used in undergraduate nursing education – students asked to try on a friend) <a href="https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Pediatric-English.pdf">https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Pediatric-English.pdf</a></li> </ul> <p><b>Advance Care Planning Guides:</b></p> <ul style="list-style-type: none"> <li>• <b>My Choices Voicing My CHOICES</b> <a href="https://fivewishes.org/shop/order/product/voicing-my-choices">https://fivewishes.org/shop/order/product/voicing-my-choices</a></li> <li>• <b>Five Wishes/ My Wishes</b> <a href="https://fivewishes.org/">https://fivewishes.org/</a></li> <li>• <b>FACE- TC</b> <a href="https://rtips.cancer.gov/rtips/uploads/RTIPS/--RT=-/WHE/DoHHS/NIH/NCI/DCCPS/7044.pdf">https://rtips.cancer.gov/rtips/uploads/RTIPS/--RT=-/WHE/DoHHS/NIH/NCI/DCCPS/7044.pdf</a></li> </ul> <p><b>Additional Reading Material:</b> Rosenberg AR, Wolfe J, Jones BL. Palliative care for children with cancer and their families. In Abrams AN, Muriel AL &amp;</p>

Actions	Strategies	Resources/Tools †††
		<p>Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 243-266.</p>
<p><b>13b. When necessary, provide youth and families with developmentally appropriate end of life care (which includes bereavement care after the youth's death).</b></p> <p><b>(Refer to Standard 14 for comprehensive post death bereavement follow up resources.)</b></p>		<p><b>Legacy Building:</b></p> <p><b>Digital storytelling: an innovative legacy-making intervention for children with cancer.</b>  Akard TF, Dietrich MS, Friedman DL, et al. <i>Pediatr Blood Cancer</i>. 2015;62(4):658–665. doi:10.1002/pbc.25337  <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4339662/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4339662/</a></p> <p><b>Finger Print Jewelry</b></p> <ul style="list-style-type: none"> <li>• <a href="http://www.regalijewelry.com/">http://www.regalijewelry.com/</a></li> </ul> <p><b>Communication about dying, death, and bereavement. A systematic review of children's literature</b>  Arruda-Colli MNF, Weaver MS, Wiener L. Communication About Dying, Death, and Bereavement: A Systematic Review of Children's Literature. <i>J Palliat Med</i>. 2017;20(5):548–559.  <a href="https://pubmed.ncbi.nlm.nih.gov/28346862/">https://pubmed.ncbi.nlm.nih.gov/28346862/</a></p> <p><b>Children's books about grief and loss</b>  <a href="https://www.apa.org/pubs/magination/browse?query=subject:Grief+and+Loss">https://www.apa.org/pubs/magination/browse?query=subject:Grief+and+Loss</a></p>

**Standard 14:**

Bereavement Follow-Up After the Death of a Child as a Standard of Care in Pediatric Oncology

Actions	Strategies	Resources/Tools †††
<p><b>14a. Following a youth’s death, a member from the healthcare team contacts the family to express condolences and assess bereavement needs.</b></p> <p><i>*Note: It is sometimes difficult to conduct a thorough assessment of risk and needs in an initial call, especially if the contact is made around the time mourning rituals are being organized or observed. Multiple calls</i></p>	<p><b>Reach out to the family to express condolences and care.</b> After the youth’s death, identify at least one member of the team, ideally someone who knew the youth who will reach out to the family. Many parents have indicated a wish for immediate outreach (e.g., within a week after the death), but if not immediately, then within three months after the death is recommended. Team members may rotate in their efforts to reach out.</p> <p><b>Track outreach efforts.</b> Track calls in a central location that the entire team can access. Prior to initiating a call to the family, check the tracker to determine if other calls have been made by other team members.</p> <p><b>Conduct preliminary assessment.</b> During the call, assess the family’s needs by inquiring about the following possible concerns in parents and siblings:</p> <ul style="list-style-type: none"> <li>• Sleep, eating, mood</li> <li>• Feelings of guilt, regret, sadness, anger, confusion</li> <li>• If at least 12 months post-loss, consider whether to further evaluate for</li> </ul>	<p><b>Evidence-based Screening and Assessment Tools</b></p> <ul style="list-style-type: none"> <li>• <b>Patient Health Questionnaire Screeners</b> - <a href="https://www.phqscreeners.com/select-screener">https://www.phqscreeners.com/select-screener</a></li> <li>• <b>PG-13</b> - <a href="https://endoflife.weill.cornell.edu/sites/default/files/pg-13.pdf">https://endoflife.weill.cornell.edu/sites/default/files/pg-13.pdf</a></li> <li>• <b>Primary Care PTSD Screen for DSM-5</b> - <a href="https://www.ptsd.va.gov/professional/assessment/screens/pc-ptsd.asp">https://www.ptsd.va.gov/professional/assessment/screens/pc-ptsd.asp</a></li> <li>• <b>Overview of Bereavement Risk Screening Tools and Efforts to Development a Self-report Risk Screener (2017)</b> - <a href="https://www.cambridge.org/core/services/aop-cambridge-core/content/view/E2A2E24277E13F0D3BD0443260C5529E/S1478951516000626a.pdf/development_of_the_bereavement_risk_inventory_and_screening_questionnaire_brisq_it_em_generation_and_expert_panel_feedback.pdf">https://www.cambridge.org/core/services/aop-cambridge-core/content/view/E2A2E24277E13F0D3BD0443260C5529E/S1478951516000626a.pdf/development_of_the_bereavement_risk_inventory_and_screening_questionnaire_brisq_it_em_generation_and_expert_panel_feedback.pdf</a></li> <li>• <b>Scoping Review of Bereavement Risk Assessment Measures (2015)</b> - Sealey M, Breen LJ, O’Connor M, Aoun SM. A scoping review of bereavement risk assessment measures: Implications for palliative care. <i>Palliat Med.</i> 2015; 29(7):577-589 <a href="https://journals.sagepub.com/doi/pdf/10.1177/0269216315576262">https://journals.sagepub.com/doi/pdf/10.1177/0269216315576262</a></li> </ul> <p><b>ICD-11 Diagnostic Criteria*</b> <a href="https://icd.who.int/browse11/l-m/en">https://icd.who.int/browse11/l-m/en</a></p>

Actions	Strategies	Resources/Tools †††
<p><i>are ideal, and the health care team member may conclude an initial call with an indication that they will call back. Such indications of a follow-up call should <u>only</u> be made if the healthcare team member is going to be able to follow-up.</i></p>	<p>symptoms of prolonged grief, including persistent debilitating grief and yearning symptoms; loss of meaning in life; and enduring symptoms of disbelief, bitterness, anger, or avoidance. <i>*Note: Intense symptoms of grief are expected to continue in grieving parents for ≥12 months; being mindful of debilitating symptoms and the potential utility of professional help is not in any way meant to pathologize parents' grief.</i></p> <ul style="list-style-type: none"> <li>• Symptoms of depression, anxiety, and/or substance abuse</li> <li>• Posttraumatic stress symptoms: Excessive intrusive thoughts, avoidance of situations that remind them of traumatic memories, hypervigilance</li> <li>• Consider thinking about posttraumatic stress symptoms, anxiety, and depression as separate from expected symptoms of grief, though there may be overlap</li> <li>• Family dynamics/conflict</li> <li>• Spiritual/religious distress</li> <li>• Inability to return to work/activities</li> <li>• Social isolation</li> <li>• If partnered, challenges with couple's coping</li> <li>• Challenges with youth's sibling(s), including persistent anxiety, changes in appetite or sleep, self-destructive behaviors, suppression of all feelings</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Major Depressive Disorder*</b> - <a href="https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f578635574">https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f578635574</a></li> <li>• <b>Prolonged Grief Disorder**</b> - <a href="https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/1183832314">https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/1183832314</a></li> <li>• <b>Posttraumatic Stress Disorder</b> - <a href="https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/2070699808">https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/2070699808</a></li> </ul> <p><i>*Note: Diagnoses should only be made by licensed clinicians.</i></p> <p><i>**Note: Intense symptoms of grief are expected to continue in grieving parents for ≥12 months; being mindful of debilitating symptoms and the potential utility of professional help is not in any way meant to pathologize parents' grief.</i></p> <p><b>Empirically-examined Bereavement Interventions†*</b></p> <p><i>*Note: Meta-analyses and systematic reviews can provide the most comprehensive syntheses of the evidence. Finding competent providers with training in grief and bereavement is key when making referrals.</i></p> <ul style="list-style-type: none"> <li>• Systematic review and meta-analysis of grief intervention trials (2019) - Johanssen M, Damholdt MF, Zachariae R, et al. Psychological interventions for grief in adults: A systematic review and meta-analysis of randomized controlled trials. <i>J Affect Disord.</i> 2019;253:69–86. <a href="https://www.ncbi.nlm.nih.gov/pubmed/31029856">https://www.ncbi.nlm.nih.gov/pubmed/31029856</a></li> <li>• Interventions for complicated/prolonged grief (2017): <a href="https://dergipark.org.tr/en/download/article-file/300164">https://dergipark.org.tr/en/download/article-file/300164</a></li> </ul>

Actions	Strategies	Resources/Tools †††
	<p>about the loss, substance use, changes in grades, or social withdrawal</p> <p><b>Schedule a meeting to answer questions.</b> When geographically feasible, and desired by the family, a meeting with the youth’s physician/healthcare team following the youth’s death that allows the family an opportunity to review the treatment trajectory and answer any questions they may have about their youth’s treatment and death.</p>	<ul style="list-style-type: none"> <li>• Systematic review of grief counselling studies (2016): Waller A, Turon H, Mansfield E, et al. Assisting the bereaved: A systematic review of the evidence for grief counselling. <i>Palliat Med.</i> 2016;30(2):132–148. <a href="https://www.ncbi.nlm.nih.gov/pubmed/26415735">https://www.ncbi.nlm.nih.gov/pubmed/26415735</a></li> <li>• Summary of treatments for prolonged grief (2012): <a href="https://insights.ovid.com/pubmed?pmid=22156937">https://insights.ovid.com/pubmed?pmid=22156937</a></li> <li>• Meta-analysis of prevention and intervention for prolonged grief (2011): Wittouck C, Van Autreve S, De Jaegere E, et al. The prevention and treatment of complicated grief: a meta-analysis. <i>Clin Psychol Rev.</i> 2011;31(1):69–78. <a href="https://www.ncbi.nlm.nih.gov/pubmed/21130937">https://www.ncbi.nlm.nih.gov/pubmed/21130937</a></li> </ul> <p><b>Interventions focused on bereaved parents:</b></p> <ul style="list-style-type: none"> <li>• Systematic review of interventions for bereaved parents (2015): Endo K, Yonemoto N, Yamada M. Interventions for bereaved parents following a child’s death: A systematic review. <i>Palliat Med.</i> 2015;29(7): 590–604. <a href="https://journals.sagepub.com/doi/pdf/10.1177/0269216315576674">https://journals.sagepub.com/doi/pdf/10.1177/0269216315576674</a></li> </ul> <p><b>Interventions focused on children and adolescents</b></p> <ul style="list-style-type: none"> <li>• Review of effectiveness of grief camps (2013): Clute MA, Kobayashi R. Are Children's Grief Camps Effective? <i>J Soc Work End Life Palliat Care.</i> 2013;9(1): 43-57. <a href="https://www.tandfonline.com/doi/abs/10.1080/15524256.2013.758927">https://www.tandfonline.com/doi/abs/10.1080/15524256.2013.758927</a></li> <li>• Meta-analysis of interventions for bereaved children and adolescents (2010):</li> </ul>

Actions	Strategies	Resources/Tools †††
		<p>Rosner R, Kruse J, Hagl M. A meta-analysis of interventions for bereaved children and adolescents. <i>Death Stud.</i> 2010;34(2):99–136.  <a href="https://www.ncbi.nlm.nih.gov/pubmed/24479177">https://www.ncbi.nlm.nih.gov/pubmed/24479177</a></p> <ul style="list-style-type: none"> <li>• Meta-analysis of bereavement interventions with children (2007):  Currier JM, Holland JM, Neimeyer RA. The Effectiveness of Bereavement Interventions With Children: A Meta-Analytic Review of Controlled Outcome Research. <i>J Clin Child Adolesc Psychol.</i> 2007;36(2):253-259.  <a href="https://www.tandfonline.com/doi/abs/10.1080/15374410701279669">https://www.tandfonline.com/doi/abs/10.1080/15374410701279669</a></li> </ul>
<p><b>14b. Offer further support and referrals, including hospital/practice bereavement services and community resources.</b></p>	<p><b>Highlight the family’s strengths and coping resources during the call.</b></p> <p><b>Tailor referrals and resources to the family’s needs.</b></p> <ul style="list-style-type: none"> <li>• <b>Medical information:</b> Respond to any questions about the youth’s medical care or facilitate connection to a medical provider who can answer the family’s questions.</li> <li>• <b>Bereavement support:</b> Offer referrals for individual, couple, and/or family counseling and support groups.</li> <li>• <b>Psychoeducation:</b> Provide resources through discussion, written materials (books), or online resources.</li> <li>• <b>Connection to other families:</b> If the family is interested, connect with other bereaved parents. <i>Note: This is best</i></li> </ul>	<p><b>Grief Information, Resources, and Organizations</b></p> <p><i>*Note: Resources below are often used and may be helpful but many have limited empirical support. In addition, some currently available resources may change over time.</i></p> <ul style="list-style-type: none"> <li>• <b>Association for Death Education and Counseling -</b>  <a href="https://www.adec.org/default.aspx">https://www.adec.org/default.aspx</a></li> <li>• <b>American Cancer Society -</b>  <a href="https://www.cancer.org/treatment/end-of-life-care/grief-and-loss.html">https://www.cancer.org/treatment/end-of-life-care/grief-and-loss.html</a></li> <li>• <b>Bereaved Parents USA -</b>  <a href="https://www.bereavedparentsusa.org/">https://www.bereavedparentsusa.org/</a></li> <li>• <b>Cancer Care -</b>  <a href="https://www.cancercare.org/tagged/grief_and_loss">https://www.cancercare.org/tagged/grief_and_loss</a></li> <li>• <b>The Center for Complicated Grief -</b>  <a href="https://complicatedgrief.columbia.edu/for-the-public/complicated-grief-public/overview/">https://complicatedgrief.columbia.edu/for-the-public/complicated-grief-public/overview/</a></li> <li>• <b>The Compassionate Friends -</b>  <a href="https://www.compassionatefriends.org/">https://www.compassionatefriends.org/</a></li> </ul>

Actions	Strategies	Resources/Tools †††
	<p><i>done with those who have parent-to-parent/mentoring training or, when that is not possible, have been screened and deemed appropriate by the team.</i></p> <ul style="list-style-type: none"> <li>• <b>Memorial services:</b> Invite to hospital-based memorial/ remembrance services.</li> <li>• <b>Financial support resources:</b> Re-assess the financial impact for the family in terms of whether their end of life/funeral expenses were met or if this has impacted the family’s grief journey.</li> <li>• <b>Continued outreach:</b> Continued outreach to family members over time is optimal (e.g., telephone, calls, emails, cards or mailed letters to especially acknowledge important dates such as birthdays, holidays, and anniversaries).</li> </ul>	<ul style="list-style-type: none"> <li>• <b>COPE Foundation</b> - <a href="https://www.copefoundation.org/">https://www.copefoundation.org/</a></li> <li>• <b>Courageous Parents Network</b> - <a href="https://courageousparentsnetwork.org">https://courageousparentsnetwork.org</a></li> <li>• <b>Evermore</b> - <a href="https://www.live-evermore.org/home/">https://www.live-evermore.org/home/</a></li> <li>• <b>National Alliance For Grieving Children Resources</b> - <a href="https://childrengrieve.org/resources">https://childrengrieve.org/resources</a></li> <li>• <b>National Cancer Institute</b> - <a href="https://www.cancer.gov/about-cancer/advanced-cancer/caregivers/planning/bereavement-pdq#section/all">https://www.cancer.gov/about-cancer/advanced-cancer/caregivers/planning/bereavement-pdq#section/all</a></li> <li>• <b>Open to Hope</b> - <a href="https://www.opentohope.com/">https://www.opentohope.com/</a></li> <li>• <b>Weill Cornell Medicine Center for Research on End-of-Life Care</b> - <a href="https://endoflife.weill.cornell.edu/grief-resources">https://endoflife.weill.cornell.edu/grief-resources</a></li> </ul>
<p><b>14c. Follow-up, ideally by someone who knew the youth, is essential when concerns are identified.</b></p>	<p><b>Obtain permission to follow up to ensure the family is able to access resources.</b> Find out the family’s preferences for follow-up (e.g., email, telephone), and offer a mechanism for them to indicate if they prefer that the team no longer follow up (e.g., by email, voicemail, or an opt-out postcard).</p>	<p><b>Additional Reading Material</b></p> <p>Rosenberg AR, Wolfe J, Jones BL. Palliative care for children with cancer and their families. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 243-266.</p> <p>Lovgren M, Sveen J. Family bereavement in pediatric oncology: In Wolfe J, Jones BL, Kreicbergs, Jankovic M (Eds): <i>Palliative care in pediatric oncology</i>. Springer International; 2018: 245-264.  <a href="https://www.springer.com/sp/book/9783319613901">https://www.springer.com/sp/book/9783319613901</a></p>

**Standard 15:**

Communication, Documentation, and Training Standards in Pediatric Psychosocial Oncology

Actions	Strategies	Resources/Tools †††
<p><b>15a. Ensure open, respectful communication and collaboration among medical and psychosocial providers, youth and families for effective patient- and family-centered care.</b></p>	<p><b>Integration into the care team:</b></p> <ul style="list-style-type: none"> <li>Regularly attend medical rounds and participate in patient care meetings and conferences.</li> <li>Offer psychosocial rounds for all staff that focuses on psychosocial issues and care.</li> <li>Provide resources for team members around effective family-team communication aimed at enhanced family-centered care.</li> </ul> <p><b>Psychosocial Consultation:</b></p> <ul style="list-style-type: none"> <li>Provide consultation to other team members and provide training to team members about psychosocial care.</li> <li>Participate in oncology journal clubs and tumor boards, sharing expertise in the emotional, social, and psychological aspects of care for youth and AYAs with cancer, that their families.</li> </ul> <p><b>Access to and utilization of medical records that provide relevant information regarding:</b></p> <ul style="list-style-type: none"> <li>Psychosocial assessment</li> </ul>	<p>Feraco AM, Brand SR, Mack JW, Kesselheim JC, Block SD, Wolfe J. Communication skills training in pediatric oncology: Moving beyond role modeling. (2016). <i>Pediatr Blood Cancer</i>; 63(6): 966-972.  <a href="https://www.ncbi.nlm.nih.gov/pubmed/26822066">https://www.ncbi.nlm.nih.gov/pubmed/26822066</a></p> <p>Baile WF, Buckman R, Lenzi R, Glober G et al. SPIKES – A six-step protocol for delivering bad news: Application to the patient with cancer. (2000). <i>The Oncologist</i>; 5(4): 302-311.  <a href="https://www.ncbi.nlm.nih.gov/pubmed/10964998">https://www.ncbi.nlm.nih.gov/pubmed/10964998</a></p> <p>Back AL, Arnold RM, Baile WF, Tulsky et al. Approaching difficult communications tasks in oncology. (2005). <i>CA Cancer J Clin</i>; 55(3): 164-177.  <a href="https://www.ncbi.nlm.nih.gov/pubmed/15890639">https://www.ncbi.nlm.nih.gov/pubmed/15890639</a></p> <p><b>Additional Reading Material</b></p> <p>Brand SR, Tarquini S, Mack JW. Communication in the Pediatric Oncology Setting. In Abrams AN, Muriel AL &amp; Wiener L, Eds. <i>Pediatric psychosocial oncology: Textbook for multi-disciplinary care</i>. New York, Springer; 2016: 7-24.</p> <p>Thompson AL, Connolly ME. Collaboration with psychosocial colleagues in the hospital setting: In BD Carter, KA Kullgren (Eds): <i>Clinical handbook of psychological consultation in pediatric medical settings</i>. Springer International; 2020: 89-99.  <a href="https://www.springer.com/sp/book/9783030355975">https://www.springer.com/sp/book/9783030355975</a>.</p>



Actions	Strategies	Resources/Tools †††
	Psychosocial intervention and follow-up plans	
<b>15b. Documentation</b>	<p><b>Psychosocial Documentation Policies:</b></p> <ul style="list-style-type: none"> <li>Follow documentation policies of the health system in which practice is undertaken.</li> </ul> <p>Policies should be in accordance with ethical requirements of their profession and state/federal laws.</p>	<p><b>Additional Resources</b></p> <ul style="list-style-type: none"> <li><b>American Psychological Association/Record Keeping Guidelines</b> <a href="https://www.apa.org/practice/guidelines/record-keeping.aspx">https://www.apa.org/practice/guidelines/record-keeping.aspx</a></li> <li><b>National Association of Social Workers</b> <a href="https://www.socialworkers.org/practice/standards/sw_case_mgmt.asp/">https://www.socialworkers.org/practice/standards/sw_case_mgmt.asp/</a></li> </ul>
<b>15c. Training</b>	<p><b>Specialized Training, Education, and Credentialing:</b></p> <ul style="list-style-type: none"> <li>Possess knowledge of developmentally appropriate assessment and treatment for youth with cancer and their families.</li> <li>Have experience working with youth with serious, chronic illness.</li> <li>Participate in ongoing relevant supervision/mentoring and peer support.</li> <li>Maintain memberships with organizations aimed at addressing and improving expertise in the psychosocial aspects of caring for youth and AYAs with cancer and their families.</li> <li>Increase knowledge base by seeking opportunities for training and professional development through participating in online webinars and attendance at workshops/conferences.</li> </ul>	<p><b>Additional Resources:</b></p> <ul style="list-style-type: none"> <li><b>Children’s Oncology Group</b> <a href="https://www.childrensoncologygroup.org">https://www.childrensoncologygroup.org</a></li> <li><b>Association of Pediatric Oncology Social Workers</b> <a href="http://aposw.org/">http://aposw.org/</a></li> <li><b>American Psychosocial Oncology Society</b> <a href="https://apos-society.org/">https://apos-society.org/</a></li> <li><b>International Psychosocial Oncology Society</b> <a href="https://ipos.wildapricot.org/">https://ipos.wildapricot.org/</a></li> <li><b>Society of Pediatric Psychology</b> <a href="https://societyofpediatricpsychology.org">https://societyofpediatricpsychology.org</a></li> <li><b>Canadian Association of Psychosocial Oncology</b> <a href="https://www.capo.ca">https://www.capo.ca</a></li> </ul>

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**Standard 14. Bereavement Follow-Up After the Death of a Child as a Standard of Care in Pediatric Oncology**

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**Standard 15. Communication, Documentation, and Training Standards in Pediatric Psychosocial Oncology**

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