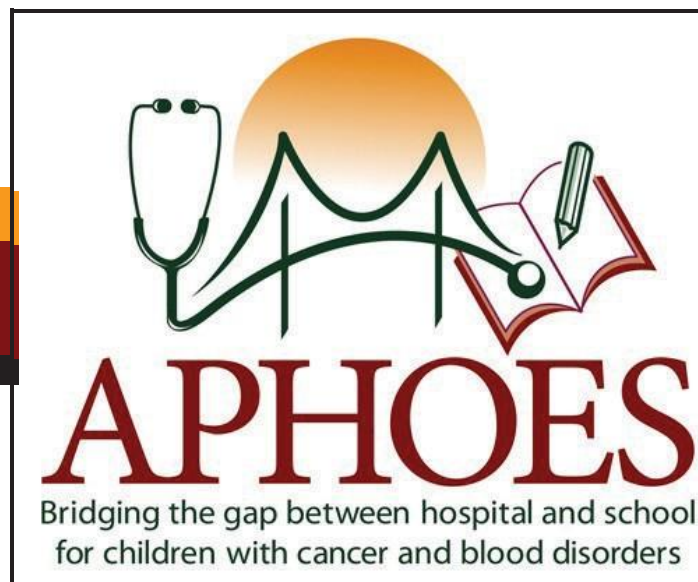


Association of Pediatric Hematology Oncology Educational Specialists

**Practice Recommendations
for Managing the Educational Needs of
Pediatric Hematology and Oncology Patients**



A Resource for Professionals
Working with Patients, Families,
Students, the Medical Team, and
School Personnel

**Version 3.0
2015**

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Preface

Children diagnosed with cancer or chronic blood disorders experience significant interruptions in school routines. Assistance should be provided to minimize the impact of illness and medical treatment on education. Assistance should also be provided to ease students' transition back to the classroom when their health allows. Hospital-based school intervention programs and identified liaisons from the medical setting should work with school personnel to provide educational assessments, planning and interventions.

The Association of Pediatric Hematology Oncology Educational Specialists (APHOES) strives to bridge the gap between hospital and school through partnership, advocacy and communication. APHOES has developed practice recommendations to provide professionals and other organizations with a framework for developing school intervention programs to meet the needs of students with cancer or chronic hematologic disorders. The intent is to increase the availability of such services for patients receiving medical care throughout the United States and to encourage future efforts in the field to develop evidence-based standards of care.

Developing these practice recommendations was particularly challenging. There are few empirical studies of the educational difficulties experienced by pediatric hematology-oncology patients and of interventions targeting these challenges. Additionally, there are few published recommendations or guidelines for school intervention programs and professionals addressing the educational needs of children diagnosed with cancer or hematologic disorders. Therefore, the APHOES practice recommendations reflect primarily the consensus-based clinical experiences and expert opinions of the APHOES membership.

Some of the empirical work informing the development of the APHOES Practice Recommendations is cited below:

- Barrera, M., Shaw, A. K., Speechley, K. N., Maunsell, E., & Pogany, L. (2005). Educational and social late effects of childhood cancer and related clinical, personal, and familial characteristics. *Cancer*, 104(8), 1751-1760. doi: 10.1002/cncr.21390
- Daly, B. P., Kral, M. C., & Brown, R. T. (2008). Cognitive and academic problems associated with childhood cancers and sickle cell disease. *School Psychology Quarterly*, 23(2), 230-242. doi: 10.1037/1045-3830.23.2.230
- Gerhardt, C. A., Dixon, M., Miller, K., Vannatta, K., Valerius, K. S., Correll, J., & Noll, R. B. (2007). Educational and occupational outcomes among survivors of childhood cancer during the transition to emerging adulthood. *Journal of Developmental & Behavioral Pediatrics*, 28(6), 448-455. doi: 10.1097/DBP.0b013e31811ff8e1
- Koontz, K., Short, A. D., Kalinyak, K., & Noll, R. B. (2004). A randomized, controlled pilot trial of a school intervention for children with sickle cell anemia. *Journal of Pediatric Psychology*, 29(1), 7-17. doi: 10.1093/jpepsy/jsh002
- Mitby, P. A., Robison, L. L., Whitton, J. A., Zevon, M. A., Gibbs, I. C., Tersak, J. M., ... Mertens, A. C. (2003). Utilization of special education services and educational attainment among long-term survivors of childhood cancer. *Cancer*, 97(4), 1115-1126. doi: 10.1002/cncr.11117
- Rey-Casserly, C., & Meadows, M. E. (2008). Developmental perspectives on optimizing educational and vocational outcomes in child and adult survivors of cancer. *Developmental Disabilities Research Reviews*, 14(3), 243-250. doi: 10.1002/ddrr.31
- Schatz, J. (2004). Brief report: Academic attainment in children with sickle cell disease. *Journal of Pediatric Psychology*, 29(8), 627-633. doi: 10.1093/jpepsy/jsh065
- Schatz, J., Brown, R. T., Pascual, J. M., Hsu, L., & DeBaun, M. R. (2001). Poor school and cognitive functioning with silent infarcts and sickle cell disease. *Neurology*, 56, 1109-1111.

The existing related practice guidelines reviewed during the development of the APHOES Practice Recommendations include:

- Children's Oncology Group. (2008, October). *Long-term follow-up guidelines for survivors of childhood, adolescent and young adult cancers (Version 3)*. Retrieved from <http://www.survivorshipguidelines.org/pdf/LTFUGuidelines.pdf>
- International Society of Paediatric Oncology. (2002, September). *Childhood cancer-Guidelines for standards of treatment and care*. Retrieved from <http://www.siop.nl/about-siop/committees/ad-hoc-committees/standards-of-care-and-training-2002-document>
- Landier, W. (ed.) (2007). *Establishing and enhancing services for childhood cancer survivors: Long-term follow-up program resource guide*. Retrieved from <http://www.childrensoncologygroup.org/index.php/research-257/survivorship-guidelines>
- Nathan, P. C., Patel, S. K., Dilley, K., Goldsby, R., Harvey, J., Jacobsen, C., ... Armstrong, F. D. (2007). Guidelines for identification of, advocacy for, and intervention in neurocognitive problems in survivors of childhood cancer: A report from the Children's Oncology Group. *Archives of Pediatrics and Adolescent Medicine*, 161(8), 798-806. doi: 10.1001/archpedi.161.8.798
- National Collaborating Centre for Cancer. (2005, August). *Improving outcomes in children and young people with cancer*. Retrieved from <http://www.nice.org.uk/guidance/csgcyp>
- Scottish Intercollegiate Guidelines Network. (2013). *Long term follow up of survivors of childhood cancer: A national clinical guideline*. Retrieved from <http://www.sign.ac.uk/guidelines/fulltext/132/index.html>

The following elements guided the development of the APHOES Practice Recommendations:

Health Questions

1. Do children with certain types of cancer or chronic blood disorders have a risk of developing educational difficulties?
2. What factors increase the risk of educational problems in children diagnosed with cancer or chronic hematologic disorders?
3. How can school intervention programs address the educational needs of children diagnosed with cancer or chronic blood disorders?
4. What type of learning problems or cognitive effects can develop in children diagnosed with cancer or chronic blood disorders?
5. What types of assessments, monitoring and interventions are recommended?
6. How can school intervention programs assist families and school personnel during palliative and bereavement care?

Target Population

School-aged children with chronic blood disorders or cancer.

Target Users

All professionals working with families, students, the medical team, and school personnel in managing the educational needs of children diagnosed with chronic blood disorders or cancer.

Funding Sources

The individuals involved in the development of the APHOES Practice Recommendations have no conflict of interest with respect to the development of this document. The APHOES Practice Recommendations were developed independently from any funding body.

Overview of Material

APHOES Practice Recommendations release dates: May, 2011. Version 1.0; September 2013. Version 2.0; and April 2015. Version 3.0

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Electronic Source

APHOES Practice Recommendations are available at www.aphoes.org.

Review and Updating

The APHOES Practice Recommendations for Managing the Educational Needs of Pediatric Hematology and Oncology Patients, Version 1.0 was issued in 2011 and updated to Version 2.0 in 2013. Version 3.0, formatted for electronic readers and digital distribution, is released in 2015. The APHOES Editorial Committee will review the Recommendations on a regular basis to determine need for updates. Updates will be noted on the APHOES website (www.aphoes.org). We suggest that professionals check this website regularly for the latest revisions and updates.

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Disclaimer

Professionals who are not regularly involved in the care of children with cancer or hematologic disorders are encouraged to consult with a pediatric hematologist/oncologist and a liaison to schools from the medical team if concerns or questions arise when reviewing or implementing the APHOES practice recommendations. The APHOES recommendations are not intended to replace clinical judgment or medical assessment. APHOES disclaims any responsibility for the application or use of these practice recommendations.

Key APHOES Practice Recommendations:

1. The need for school support begins at diagnosis. As soon as possible, a single professional based in the hospital should be designated as the school liaison for each child diagnosed with cancer or a chronic hematologic disorder.
2. Soon after diagnosis, the liaison working with the child, family and school staff should create an academic plan.
3. Clear, on-going communication between the liaison, child, parents, and teachers is essential. In particular, a meeting should be considered upon the child's return to school, at the beginning of an academic year, and/or when the child transitions to a new school.
4. School attendance is encouraged as soon as it is medically safe and appropriate. Factors such as infection risk due to neutropenia, safety of external central lines, and mobility should be balanced against the improvements in quality of life associated with school participation.
5. Factors to be considered when assessing a child's ability to attend school relate to the child's condition and treatment. The student's psychosocial readiness, pain level, degree of fatigue, strength and, for a student with cancer, the degree of bone marrow suppression should all be assessed. Consideration must be given to treatment type, duration, and frequency.
6. Children at risk for educational difficulties because of their illness and/or treatment should be identified, assessed, and monitored. Risk factors to consider include: diagnosis, treatment, age, gender, functioning, family history, impairments, chronic illness, barriers to services, prolonged interruption in academic instruction, and/or a difficult transition back to school.
7. A meeting including the liaison and/or others from the medical team, student, and family should occur prior to the student's return to school to discuss the family's concerns, fears, and expectations, and to plan for and facilitate the student's smooth transition back into the classroom. If a meeting involving all of these parties is not feasible due to distance between the hospital and school or other factors, the liaison and medical team should provide consultation on these issues to the family and school via telephone or video-conferencing.
8. If feasible, a classroom presentation should be made prior to the child's school re-entry, particularly for children in the elementary grades. Otherwise, the liaison should work with the teacher and school nurse to determine alternative methods to prepare and educate classmates.
9. Children's academic progress and psychosocial adjustment should be monitored annually for as long as they are attending school. Students whose disease and/or treatment place them at-risk for neurocognitive late effects should receive periodic neurocognitive testing as part of their long-term care.
10. In the event that a child with cancer or chronic hematologic disorder transitions to palliative care, a plan should be developed to accommodate the child's desire to remain connected with classmates and maintain participation in school during this time. The plan should address the child's needs as well as the impact on classmates and faculty as the child withdraws from school involvement as the end of life nears. Planning should include input from the child, parents, educational liaison on the medical team, medical professionals, and school faculty (teachers, school nurse, and psychologist/social worker).
11. Resources should be made available (e.g. educational materials, support group services) to school faculty, students, and families during the child's palliative care as well as after the child has died.

Acknowledgments

APHOES members worked collaboratively, writing The APHOES Practice Recommendations to identify and address the educational needs of children with cancer and blood disorders. This resource was developed for professionals working with and caring for these children. The purpose was to develop written recommendations and a comprehensive resource. We would like to express our gratitude to the contributors who worked countless hours, shared ideas and experiences, and information regarding “best practices”. We would like to thank the APHOES members for their time, knowledge, expertise and contribution to this project during meetings held over the past several years. You are truly a dedicated, committed group of professionals. With your motivation, enthusiasm, and energy, we approached the “starting line”.

Although numerous people have contributed to the development and completion of this project, there are a few for whom special thanks are in order.

Kathryn Kirkpatrick, PhD, LISW-S, Nationwide Children’s Hospital, thank you for your hard work “getting us started” with Chapter 2 which provides detailed information on making initial contact and taking the first steps with families and schools.

Norman Fried, PhD, we appreciate the work you do in palliative care and bereavement. Your contributions were invaluable and we thank you for sharing some of your previously published work in this guide. For some children, sadly, their disease progresses and they no longer respond to treatment. This delicate subject must be approached in the most gentle and compassionate way. It is during this most difficult and challenging time in a patient’s life that the educational liaison works to support families, staff and school communities. Dr. Fried guided us with his expertise and gave us the tools to cross that “finish line”. We thank you.

Special thanks to Marnie Hauff, BA, School Liaison, Pediatric Division of Hematology/Oncology, Washington University School of Medicine, St. Louis Children’s Hospital, for offering your skill and talent, reviewing the guide, and for your helpful recommendations.

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Thank you to all of the educators who have shown tremendous support in accommodating each child’s educational needs and facilitating a smooth baton hand-off during the educational relay. You are a vital part in the lives of these children.

Finally, our true inspiration has come from the many children and their families who have shown courage and perseverance in the midst of their many challenges. Often times, it is these children who have set the pace for navigating the course. Thanks to the parents who have also made education a priority in the lives of their children. Every child in the United States is entitled to a free public education in the least restrictive environment. Through the recommendations outlined in this handbook, it is our hope that professionals have access to the tools to become the advocates for children whose education is complicated by cancer or hematologic disorders.

Chapter 1

Mapping the Course: Introduction to School Intervention Programs

The Charge - School for All

In the United States alone, each school day 46 children are diagnosed with cancer, over 12,000 children annually. The 5-year survival rate for all childhood cancers combined has increased to approximately 80% (Ries et al., 2004). As the number of childhood cancer survivors continues to increase, so does the number of pediatric cancer patients and survivors attending schools. Moreover, as medical care improves the functioning and quality of life for children living with chronic blood disorders, such as sickle cell disease, aplastic anemia, and Gaucher Disease¹, more of these patients are able to participate regularly in school activities and rigorous academic pursuits than ever before. Thus, it is imperative that pediatric hematology-oncology medical teams, hospital administrators, and community-based educators across the country increase their coordinated efforts to understand the implications of these diseases on students' lives and to develop programs in hospitals and in schools to maintain these students' educational progress despite the challenges presented by their medical histories. A free and appropriate education is the right of *all* children in the United States.

School is the central arena for academic and social development throughout childhood and adolescence. By participating in school activities and acquiring new academic skills, children and teens have opportunities to feel accomplished, develop friendships, and prepare themselves to be productive members of the adult world. For children with life-threatening medical conditions, participating in school is doubly important. In addition to the benefits described above for all students, school involvement provides children with life-threatening health conditions a sense of normalcy in the midst of their very abnormal medical circumstances. School offers them a sense of hope about the possibilities for their future. Thus, it is imperative that children and teens, *regardless* of their medical histories and current health circumstances, are provided with meaningful opportunities to participate as fully as possible in school communities and academic pursuits.

Challenges for Patients, Parents, and Teachers

This charge, of course, is much easier said than done. Attending school, maintaining connections with classmates and teachers, and continuing to develop academic skills while being treated for cancer or a chronic hematologic disorder are all difficult to do. Students in these circumstances struggle to overcome the many obstacles and hurdles presented by their medical conditions, and their parents and teachers struggle to help them negotiate these challenges to their school involvement. In the case of pediatric cancers, the challenges to school participation include months or years of medical treatment that are often necessary for cure. Students with cancer typically miss several months of school during the most intensive phases of treatment, and many cancer patients subsequently have a prolonged period of milder "maintenance" therapy when they intermittently attend school. Students with chronic blood disorders also have high rates of school absenteeism due to repeated symptom flare-ups and/or infections that require hospitalizations or intensive home care. Aside from frequent and/or prolonged school absences, other physical factors that disrupt learning and school participation for pediatric hematology-oncology patients include: fatigue, pain, nausea, newly acquired physical disabilities (as in the case of a recent amputation or limb salvage surgery), newly acquired cognitive impairment as a result of neurotoxic treatment, or a neurological complication such as a stroke or an intracranial bleed, and/or newly acquired hearing or visual impairments. Cancer patients and hematology patients also struggle to cope with the psychosocial implications of their medical conditions. Feelings of sadness, anxiety, self-consciousness about illness-related physical changes and isolation from peers can cause students to avoid school events and social activities.

Parents of students with cancer or chronic blood disorders are often at a loss for how to help their children stay connected and remain academically productive during periods of extended and/or intensive medical care. In the midst of a medical crisis, it is difficult for parents to prioritize their child's educational needs when so much medical attention is necessary and they are wrestling with their own fears and worries about their child. Moreover, parents are often overwhelmed with the demands of their child's medical care and learning to navigate the complex medical world. Parents' time, attention, energy, and financial resources are typically spread too thin between their sick child's medical care, care for their other children, home care, and work responsibilities. Additionally, when it comes to advocating for an ill child's educational needs, many parents are limited by a lack of knowledge about their child's educational rights, the laws established to ensure their child an appropriate education, and how to effectively navigate the educational system.

Concurrently, teachers and school administrators, who want to be helpful to families in medical crisis, are often at a loss too. They lack the medical expertise to anticipate the likely impact of cancer or a hematologic disorder on the child's school participation and educational needs. Teachers do not want to burden families in medical crisis with school concerns; yet, they often are the first to observe a child's lack of academic progress, increasing social withdrawal, or behavioral regression in the classroom. Other factors complicating teachers' and administrators' contributions to educational planning for students with cancer and hematological disorders include their own personal experiences with serious illness and the expectations borne out of these experiences. For instance, without realizing it, a teacher who has lost a family member to cancer may distance himself somewhat from a seriously ill student and her parents as a protection from experiencing a sense of loss again. The resources available in a particular school district may also limit educational planning for students. Teachers' and administrators' uncertainty and frustration about the limits of what can be offered to students with significant illness can complicate collaborative planning efforts between students, parents, school staff and the medical team.

Initial Response to the Challenges - School Intervention Programs

In short, maintaining students' education in the face of serious medical illness such as cancer or a chronic hematologic disorder is a daunting, complicated task for all parties involved. As advances in medical supportive care have enabled more children to return to the classroom during treatment, pediatric centers have responded by offering school support services of one kind or another to their patients. The kind of school support services offered varies tremendously from one medical institution to another. Some institutions have developed formalized school support programs with staff dedicated to only this kind of patient care. Other institutions have folded school support services informally into pre-existing medical staff job descriptions; that is, nurses, social workers, or child life specialists address school issues with patients as time allows in the context of other primary job responsibilities in the medical center.

School intervention programs across pediatric centers also vary significantly in the kinds of services they provide. Some pediatric hematology-oncology clinics offer school support services beginning at diagnosis, providing community-based schools with information right away about a child's newly diagnosed medical condition and its expected impact on school attendance and participation. However, more commonly, pediatric hematology-oncology clinics offer "school re-entry" services. The purpose of school re-entry services is to facilitate patients' re-integration into the classroom after prolonged absences due to treatment. These school re-entry services generally include a classroom visit by a member of the medical team to explain the patient's illness in developmentally appropriate terms and provide his/her peers with suggestions for how to emotionally support their returning classmate. School re-entry services may also include a meeting attended by the returning student's parents, teachers, school administrators, and members of the hospital medical team or school support team. The general purpose of such a meeting is to provide the school with needed information about the child's medical condition and collaboratively develop an initial educational plan for the returning student.

With the increasing focus on cancer survivorship in recent years, some pediatric institutions have focused not on school re-entry, but rather school assistance for youth in the years following completion of treatment for cancer. One purpose of these school support services is to educate schools about the long-term or "late effects" of cancer treatment. There is well-established research demonstrating that certain types of cancer treatment put youth at risk for deficits in learning and memory. These deficits may emerge years after treatment has ended, and if unrecognized can precipitate a downward spiral of school failure and hopelessness in students. School support services for cancer survivors generally include a neuropsychological assessment to identify patients' unique profile of neurocognitive

strengths and weaknesses. By educating students, family members, and school personnel about the late effects of cancer treatment, all parties are better able to make appropriate educational plans for cancer survivors to maximize their rehabilitative potential.

The variability in school support services across pediatric medical institutions stems from several factors. First and foremost, funding significantly dictates the kinds of services that can be offered. Some school support services are funded internally by a medical center; other school support services are funded with philanthropic gifts or community agency grants. Unfortunately, school support services are rarely revenue generating; these services are not covered by medical insurance; schools often do not have funding to cover the cost of consultation by medical staff; and patients' families are already struggling to cover the costs of expensive medical care. The priorities of funding agencies, hospital administrators, and/or community agencies in terms of services for newly diagnosed children, children in the midst of treatment, or children receiving long-term survivorship care contribute to the availability of different kinds of school support services across institutions.

What's Needed – Comprehensive Programming

It is the firm belief of many professionals and educators working with pediatric hematology-oncology patients that comprehensive school intervention programs should be a recognized and widely adopted standard of care for these patients. Failing to do so puts these patients at risk for a course of academic and psychosocial derailment during treatment that is extremely hard to overcome when treatment or the medical crisis is over. Too little attention to the educational challenges faced by patients, families, and teachers, and the provision of piecemeal school support services have dire consequences for individual patients as well as for society at large in terms of lost potential for achievement and productivity.

To this end, the Association for Pediatric Hematology-Oncology Educational Specialists (APHOES)² has published this handbook to provide recommendations for the provision of comprehensive school support services to pediatric hematology-oncology patients. These recommendations represent the collective expertise and current practices of the membership of APHOES. Ideas for these recommendations were exchanged, expanded upon and revised in small group discussions over the course of four annual meetings. Members contributing to this effort come from more than 20 different institutions and organizations across the U.S. and have a variety of professional backgrounds including medicine, nursing, social work, child life, education, special education, and psychology. The unifying factor among our membership is that all members are involved at their home institutions or organizations in helping pediatric hematology-oncology patients and survivors, their families, and community-based educators overcome the challenges cancer and chronic blood disorders present to students' academic progress. Gathering the collective expertise of the APHOES membership, as presented in this handbook, is an important first step to developing evidence-based practice guidelines. Critical next steps for APHOES members and the broader field of pediatric hematology-oncology educational specialists include initiating carefully conducted research to demonstrate the specific benefits of different aspects of school support programming and identifying ways of effectively tailoring the provision of school support services to students with different personal, family, and community-based school resources and limitations. As pediatric centers develop school support services in the current economic climate, it is critical that program evaluation studies are conducted to ensure that students are benefiting and that the limited funding available for this kind of clinical service is invested responsibly.

The APHOES handbook outlines the kinds of intervention services recommended to address the educational and academic needs of students with cancer or hematologic disorders throughout the course of their treatment. The recommendations are written broadly so professionals throughout the country can use them. However, there are state-to-state variations in how federal education and special education laws are interpreted and implemented. Additionally, states have their own education policies. Thus, these recommendations should be used as a template describing needed services across the treatment continuum and also as a "go-to" resource for concrete suggestions for effectively providing these services to a student at a particular point in his or her treatment. To these ends, the chapters of this handbook include both detailed text addressing service issues across the treatment continuum as well as easy-to-use checklists and bulleted outlines for quick reference by service providers. Professionals are advised to supplement the APHOES recommendations with information about the education policies and implementation of federal education law in the state(s) in which they work and their students reside. This state-specific information can be obtained most reliably from consultation with the Director of Special Education for a specific school district.

APHOES Recommendations – An Overview

Although a goal of APHOES is to foster the development of comprehensive school intervention programs across the country for children with cancer and hematologic disorders, it is well recognized that at most medical institutions, program development will be slow and often occur in a piecemeal fashion. Depending on funding and institutional priorities, services will be developed first, for instance, to facilitate students' school re-entry or to provide neurocognitive testing to cancer survivors. Hence, although the chapters that follow address needed services across the treatment continuum, each chapter can be used as a stand-alone resource. That is, if a professional is looking for help specifically about how to conduct an effective classroom visit for a dying child, the chapter "Time. . . Support During Palliative and Bereavement Care" may be consulted for an outline of important topics to cover with a student's classmates given their developmental level.

As indicated by the variety of professional backgrounds represented in APHOES, the staff tending to school issues for pediatric hematology-oncology patients and survivors varies across institutions. In light of this fact, the term "liaison" was adopted in the chapters that follow to refer to the specific staff member helping a student and family manage school-related concerns. One staff member may fill the liaison role for all hematology-oncology patients at an institution, or different staff members may fill the role for different patient populations. It is critical though that a specific liaison is identified for each patient/student to act as the point person for his or her family and school staff in regards to school and academic matters. Although the liaison often refers the family and/or school personnel to other members of the healthcare team at an institution for specific kinds of assistance or intervention, an identified liaison is essential for continuity of care and best communication practices for a particular family, hospital, and school.

The chapters of this handbook are titled with loose reference to the components of a race (i.e., "Mapping the Course", "Getting Started", "Ready, Set, Go..."). In many ways, meeting the educational needs of a student coping with cancer or a chronic hematologic disorder is a race – a race to ensure that steps are taken to avoid, or at least minimize, the student's academic and social derailment during the course of treatment and afterwards. Once a course of academic or social derailment begins, it is very difficult to recover. It is much better for students to stay on track from the get-go and throughout treatment with necessary supports. Importantly, the race is not a short distance sprint, but a marathon, completed best with steady pacing and a reliable, well-informed support crew.

Briefly, the remaining chapters of this handbook address the following topics:

- Chapter 2, *Getting Started*, outlines the tasks to be accomplished by the liaison from the hospital around the time of a child's diagnosis. School intervention services at this time focus on an exchange of information between family, school, and medical team via the liaison and collaborative formulation of a plan for how to maintain the child's connection to classmates and academic progress during treatment.
- Chapter 3, *Staying on Track*, provides liaisons with concrete suggestions for monitoring how well plans for continuing a child's education and social connectedness during treatment are being implemented and how well they are working as the child's medical status changes over the course of treatment.
- Chapter 4, *Ready, Set, Go . . . School Re-Entry*, addresses the needs of students around the time that they are medically cleared to return to school. Detailed outlines of important topics to cover with school faculty and classmates during school visits are provided.
- Chapter 5, *Moving Forward . . . Childhood Cancer Survivorship*, pertains specifically to school issues for survivors of pediatric cancer. Treatment-related late effects impacting learning and academic performance are discussed as well as factors increasing a child's risk for these late effects. Recommendations are provided regarding neuropsychological assessments, academic accommodations, and interventions for childhood cancer survivors experiencing late effects.
- Chapter 6, *Obstacles and Hurdles*, concerns the unique circumstances and needs of children living with chronic hematologic disorders. Although generally speaking the educational needs of these students are similar to those of children with cancer; the chronicity and episodic nature of many blood disorders present some unique issues for families, schools, and medical teams to resolve.

- Chapter 7, *Time . . .*, addresses the unique needs of a subgroup of children. It discusses the needs of children whose disease has progressed to the point of being terminal. Specifically, recommendations are made for preparing school faculty and classmates for the dying child's participation in the classroom. Additionally, strategies for helping children of different ages cope with grief are outlined.
- Chapter 8, *Back of the Pack*, reviews the academic and psychosocial impact that a diagnosis of cancer or blood disorder has on the sibling. Detailed outlines of important topics to cover with school faculty and classmates during school visits are provided.

The appendices include additional ready-to-use materials for professionals providing school intervention services to children with cancer or hematologic disorders.

- *Appendix A* is a sample consent form for obtaining parents' or guardians' permission to exchange information with a patient's school for the purposes of educational planning. The liaison should use a form that has been approved by their own institution to meet confidentiality requirements.
- *Appendix B* is a sample intake form that can be used for gathering pertinent information about a patient's school and family history at the time of diagnosis.
- *Appendix C* lists helpful books for children, teens, parents, and teachers.
- *Appendix D* addresses common questions that arise at a classroom visit for a student who has died.
- *Appendix E* includes cancer resources for students, parents, and educators (hospital-based as well as community-based).
- *Appendix F* includes hematologic disorder websites & organizations for students, parents, and educators (hospital-based as well as community-based).
- *Appendix G* is a compilation of college scholarships available to patients and cancer survivors. Available scholarship programs are always changing so the list included in this handbook should be considered a starting reference list which students and educators should supplement with their own updated research.
- *Appendix H* is a glossary, which includes explanations of terms used in this handbook as well as terms used in the broader literature of school issues and interventions for pediatric hematology-oncology patients. Because there are geographic variations in terminology related to education and education law, it may be helpful to review the glossary prior to reading the chapters of this handbook.
- *Appendix I* is an annotated bibliography of sources consulted for and relevant to the topics addressed in this handbook related to school issues for children and adolescents during and after cancer treatment.
- *Appendix J* is an annotated bibliography of topics addressed in this handbook related to school issues for children and adolescents with hematologic disorders.
- *Appendix K* includes sample letters and forms regarding the needs of patients with cancer and/or hematologic disorders.
- *Appendix L* is a list of resources related to the needs of siblings in the school.

NOTES

¹These are some of the most common chronic blood disorders presenting challenges to patients' educational progress and participation; others include Idiopathic Thrombocytopenic Purpura (ITP), bone marrow failure syndromes, hemolytic disorders, bleeding disorders, and auto-immune disorders.

²APHOES was established a) to facilitate the exchange of expertise among professionals involved in meeting the educational needs of students with cancer or hematologic disorders, and b) to advocate at the local, state, and national level for the educational needs of these students.

REFERENCE

Ries, L. A. G., Melbert, D., Krapcho, M., Mariotto, A., Miller, B. A., Feuer, E. J., ...Edwards, B. K. (eds). (2007). *SEER cancer statistics review, 1975-2004*. Retrieved from <http://seer.cancer.gov/csr/1975-2004>

Chapter 2

Getting Started: Making the Initial Contact with Patients, Families, and Schools

When a child is newly diagnosed with cancer or a blood disorder, school-related matters should be addressed as soon as possible. The team of professionals caring for the child, and most likely involved in addressing these matters include: physicians, nurses, child life specialists, psychologists, social workers, and educational liaisons. Upon diagnosis, a team member should be identified as the primary point person to coordinate school-related services. In this guide, the point person will be referred to as the “liaison”. The discipline of this liaison may vary from institution to institution, but a specific person should be assigned the role. The liaison is someone who has a working knowledge of education law, an understanding of the educational needs of children with cancer or blood disorders, and the resources available to communicate with local school district personnel. This chapter will explore the liaison’s initial steps in contacting the family and school as well as facilitating the child’s academic instruction during treatment.

Each institution/team should have a mechanism in place for informing the liaison of a new patient. Referral forms, verbal communication, or regularly scheduled patient rounds are often utilized. Coordination of school services and the development of a plan of action must be established so that the medical team, parents, and school personnel all know what to expect. Communication should be ongoing so that the child’s academic needs and progress can be monitored.

It is important to convey to parents and school personnel that maintaining school progress is vital during and after treatment. It is not uncommon for parents and/or teachers to de-emphasize and defer school with the intention of minimizing pressure on the student and family. However, school is the work of children, and they need to maintain that aspect of life in as normal a way as possible. It may be useful to encourage early and regular parent/teacher conferences for updates, assessment of academic performance and necessary interventions. Informing the parents of the educational rights of their child can empower them to advocate for needed services. Most students who are unable to attend school due to illness are eligible to receive home-based instruction¹ services from their public school system.

Parents should be given accurate information about the accommodations that may be available depending on the student’s grade level, educational plan, and federal and state laws. Any worries or concerns communicated by parents, students, or school personnel should be recognized and addressed appropriately by the liaison. The liaison plays a crucial role in bridging the gap between the hospital, school, and home.

Below are helpful tips to consider when making initial contact with families and schools.

Initial Contact with New Patient and Family

1. Gather information about diagnosis, treatment, and side effects
2. Introduce services to family
 - Educate family about importance of continuing school during illness
 - Explain education system to family
 - Obtain consent for communication with the school (See Appendix A)

Interview with Patient and Family

1. Use a standardized form for gathering information (See Appendix B)
2. Have a system to document the liaison's plan
3. Ask questions in multiple ways to get accurate information
4. Obtain information for provision of services
 - Date of diagnosis and date of intake
 - Diagnosis, relapse information
 - Demographic information
 - Makeup of household/family
 - Contact information for child's school and school district offices
 - Primary contact person at the school
 - Type of school (public, private, charter, online)
 - Any siblings in the same school
 - Family's goals for school services/education of the ill child
5. Obtain child's education history
 - Preschool attendance
 - Age at school entrance
 - School attendance history
 - Active 504 Plan or Individualized Educational Plan (IEP) information
 - Any existing services or interventions in place
 - Need for English as a Second Language/English Language Learner (ESL/ELL) instruction
 - Current grade
 - Any grade(s) repeated/retention history
 - Learning concerns identified by parent or school
 - Any past neuropsychological testing or school-based testing

Initial Contact with School

1. Identify a primary school contact person (examples include principal, assistant principal, guidance counselor, school nurse, teacher, school psychologist, or school social worker)
2. Identify/establish a system of communication with school (phone, email, and/or written correspondence)
3. Provide initial information to the school (once parental consent is obtained)
 - Diagnosis, treatment and prognosis
 - Treatment dates
 - Attendance expectations/anticipated absences
 - Initiate home-and hospital-based instruction
 - Contact information for hospital liaison
 - Tentative school re-entry date

Facilitation of Home- and Hospital-based Instruction

1. Inform parents about educational rights/laws
2. Develop a written plan with community-based school district for services (home-based instruction plan, 504 Plan, IEP under 'Other Health Impairment' category)
3. Advocate to have the classroom teacher be the home-based instructor when possible
4. Advocate for intermittent home-based instruction with partial school attendance (if and when appropriate).
5. Identify private school students and discuss their options
 - Dis-enroll from private school and enroll in public school to obtain home-based instruction services
 - Self pay for tutor to use private school curriculum
 - Negotiate services from private school using tuition payments
6. Explore appropriateness and availability of online distance learning courses or educational programs
7. Discuss specific grade-based requirements
 - Standardized state assessments
 - AP exams
8. Recognize district-specific requirements, especially regarding paperwork
9. Encourage communication and collaboration between classroom teacher and home-based and/or hospital-based instructor
10. Discuss modifications and accommodations for home-based instruction and then for school re-entry
11. Maintain ongoing communication with classroom teacher and home-based instructor
12. Encourage parents to maintain attendance records for any home-based instruction services that are provided by the school
13. Begin preparation for return to school with family and school

Topics to Discuss During Follow-up Communication with School

1. Implication of diagnosis for academic progress (short term and long term)
2. Reasonable academic expectations
3. Anticipated length of absence
4. Possible changes in learning due to disease and treatment
5. Home-based instruction workload adjustments
6. Effects of social isolation
7. Physical changes/body image issues
8. Emotional impact on other students
9. Special circumstances within the school (another student or staff with illness, cultural issues, recent losses)
10. Recommendations for peer contact/classmate communication with ill student
11. Prognosis, when appropriate
12. Treatment plan (inpatient vs. outpatient care)
13. Home-based instruction vs. hospital instruction
14. Needs of siblings in same school or district
15. Contact information of medical team for further questions
16. Available school re-entry services
17. Transition plan for school reentry

The liaison facilitates the development of an effective school plan by providing information about the student's medical condition and the anticipated course of treatment. It is necessary for the school to receive written documentation of the child's medical diagnosis and treatment plan in order to initiate home-based instruction and to provide educational accommodations. In addition, it is beneficial for the liaison to provide information about the possible impact of the student's medical condition on his psychosocial and educational functioning. The liaison should address the following topics with school personnel and can provide helpful written materials when initiating home-based and/or hospital-based instruction.

Information for Schools and Classroom Teachers

1. Medical documentation
 - Patient-specific letter
 - Diagnosis information
 - Anticipated treatment plan
 - Anticipated length of absence
 - Request for home-based instruction
 - Medical documentation for 504 Plan or IEP process, if necessary
 - General information
 - Diagnosis-specific information
 - General treatment information
 - Literature from organizations such as Leukemia & Lymphoma Society or CureSearch
2. Psychosocial resources
 - Suggested reading for adults and classmates (see Appendix C)
 - Consider classroom visit at time of diagnosis to address the questions and concerns of classmates
 - Activities to promote/maintain peer relationships/connections
 - Create classroom mailbox
 - Suggest daily/weekly "mystery caller" from classroom
 - Maintain child's desk in the classroom
 - Save child's seat with a stuffed animal ambassador
 - Call child's name at attendance
 - Display child's work in the classroom
 - Utilize Skype/webcam to participate in social or academic activities, including lunch
 - Utilize Facebook/Caring Bridge websites
 - Include child in celebrations and special events
3. Educational/Academic information
 - Discuss academic expectations prior to re-entry
 - Maintain records of academic progress
 - Identify potential risk for educational difficulties and cognitive effects

NOTE:

¹ There is regional variation in the term used to describe academic instruction services offered by public school systems to students who are unable to attend school due to illness. The term chosen for this guide is "home-based instruction". "Homebound instruction" and "home tutoring" are common variations. The liaison should make a point to learn the specific term used by the local school systems.

Chapter 3

Staying on Track: Monitoring Academic Progress and Performance

Following a child's diagnosis of cancer the liaison plays an important role in promoting continued involvement in school. The extent to which a child being treated for cancer is able to participate in school will vary depending on a number of individual and treatment-related factors. While some children will be able to attend school at least part-time during their treatment, others will be unable to attend school at all for up to a full year or longer. This means that while some children will be able to receive at least some school-based instruction, others will require hospital-based instruction, home-based instruction, or some combination of these. In some treatment centers hospital teachers will provide hospital-based instruction and in others, teachers from the child's school district will provide instruction. Regardless of the instructional model, it is vital that the liaison monitor the student's educational services and academic progress to ensure that the child's instructional needs are being met.

There are many factors that can promote or impede a student's learning during treatment. Hence, it is critical that efforts are made to monitor both a student's academic progress as well as the provision of instruction and educational services across the hospital, home, and school settings. This monitoring should occur at predictable "touch points" during and following treatment. Effective monitoring of a student's academic progress and educational services typically involves face-to-face discussions with the student and family during clinic visits as well as phone conversations with teachers and other school personnel. The liaison can "touch base" during any regularly scheduled clinic visit, although recommended touch points include visits during the first quarter of each new school year and anytime a student transitions to a new school, such as from elementary to middle to high school, or relocates to a different school. The monitoring provided by the liaison is all the more important once the student is medically cleared to resume attending school. For many students, the return to school involves part-time attendance, at least initially, and the continued combination of hospital- and home-based instruction for a significant period of time, whether this is a period of several months, a semester, or entire school year. For this reason, school re-entry or re-integration is not an all or none, one-time event, but rather a lengthy, dynamic, transitional process.

Clear, on-going communication between the liaison, student, parents, and teachers is essential to a successful transition from on-treatment to off-treatment and from part-time to full-time school attendance. *Each new school year*, a point person from the school should be identified by the family to exchange information with the liaison and with home-based instructors. (Note: It is important to be sure that previously signed consents permitting school-to-hospital communication continue to be updated each new year; [See Appendix A.](#)) Families should be strongly encouraged to *initiate* a discussion with their child's teacher(s) each fall about their child's medical history and its impact on his previous and current school attendance and participation. Putting parents/families in charge of initiating this conversation ensures that necessary information about the student is passed on to subsequent teachers from one year to the next.

The following is a list of goals for on-going academic monitoring.

Primary Goals for Academic Monitoring

1. Inform teachers of the probable short- and long-term effects of the student's cancer and treatment that may impact the student's learning and school participation
 - Frequent absences and interruptions in learning due to outpatient visits/hospitalizations
 - Hearing loss
 - Changes in vision
 - Fine and gross motor impairments
 - Fatigue
 - Inattentiveness
2. Assist the school in developing an appropriate educational plan for a student given the physical, cognitive, and behavioral challenges related to the disease and treatment
3. Determine that educational plans are being implemented consistently in the classroom
4. Monitor academic progress/school performance and stay abreast of any changes to a student's academic accommodations and services at school provided through a 504 Plan or Individualized Educational Plan (IEP)
5. Ensure that hospital-, home-, and school-based instruction are well-coordinated and are occurring as scheduled
6. Coordinate academic accommodations and services that, as available, best meet the language and cultural needs of the child and family

It is important that the liaison keep updated records of information related to the primary goals. Parents/families should be advised of the importance of maintaining records of their child's evaluations, progress reports, 504 Plans, and IEPs as well.

Outlined below are key issues to address and record during periodic monitoring of the student's academic progress and instruction across school, home, and/or hospital settings. Much of the information can be obtained by the liaison during clinic visits and/or via periodic phone calls. Supplemental reports obtained directly from school-, home-, and hospital-based instructors may provide for a more accurate and comprehensive assessment. Ultimately, the ease with which a child is able to transition back into the classroom following treatment is dependent upon the extent to which the instruction received during treatment and during the transition back to full-time school attendance addressed the student's academic and psychosocial needs. The liaison plays an important role in monitoring the child's academic progress while he is unable to attend school full-time and in monitoring the extent to which the instruction provided meets his needs. There are important points for the liaison to consider in gathering information regarding academic instruction provided at the hospital, in the home, and at school during treatment.

Key Issues for Monitoring Hospital-Based Instruction and Academic Progress

1. Family/child perception of hospital-based instruction during admissions
 - Does family/child feel hospital-based instruction is appropriate and beneficial?
 - Does family/child feel that hospital admissions should only involve illness-related therapy and that schooling should take place out of hospital setting?
 - Are school-related issues addressed by the treatment team during hospitalizations?
 - Has the child received consistent hospital-based instruction?
 - Overall, how satisfied is the family/child with hospital-based instruction?
 - Does student appear to work to the best of his/her ability during instructional sessions with the hospital-based teacher or tutor?
 - Does student participate willingly in hospital-based instruction or tutoring and independently complete work?
 - Is the observed rate of academic progress in line with expectations given treatment course and health status?

2. Strengths and weaknesses of hospital-based instruction
 - Is there a place allocated for instruction in the hospital?
 - Is there coordination between hospital treatment schedule and hospital-based instruction that works best for the child/family/hospital staff/instructor?
 - Is hospital-based instruction incorporated in the hospital treatment plan?
 - Is the child comfortable, rested and well fed prior to the lesson?
 - Does the child "look forward" to hospital-based instruction?
 - When a teaching session is in progress, are there limited distractions/interruptions during the lesson (no IV pumps beeping, no medications needed, no phone calls, television is turned off, child is comfortable, no visitors present)?
 - Does a family member remain with the child during the teaching session?
 - If the child is hospitalized over a school break, is instruction still provided?
3. Efficiency and effectiveness of communication between family, school, and hospital-based instructors when admitted and discharged
 - Does the family have a direct contact number for the hospital-based instructor?
 - Does the hospital-based instructor have a direct contact/number for the family?
 - Is it easy for the family to contact the hospital-based instructor?
 - Is it easy for the hospital-based instructor to reach the family?
 - Are messages for each party returned in an efficient manner?
4. Timely access to hospital-based instruction during admissions
 - Is the hospital-based instructor informed ahead of time about scheduled admissions?
 - Is there a mechanism in place to arrange hospital-based instruction in the event of unscheduled hospital admissions?
 - How often has the hospital-based instruction been scheduled?
 - How often has it been provided?
 - If a school district employee provides instruction during hospital admissions by, have potential barriers been addressed? (Is the hospital located within a reasonable distance for the instructor; is free parking available?)

Key Issues for Monitoring Home-based Instruction and Academic Progress

1. Scheduling
 - Does the family or instructor schedule home sessions?
 - Is there flexibility with scheduling (around treatment, best time of the day for the child, how often per week, how many hours per visit)?
 - How often is home-based instruction scheduled?
 - How often is that schedule observed; does it change frequently?
 - If the schedule is changed, for what reasons (clinic visits, child ill, or instructor not available)?
 - What is the scheduled length of each home visit (hours)?
 - If home visits last less than the scheduled length, what are the reasons?
 - Is the time of the day for each home-based instruction visit the same or variable?
 - What determines the time of day that the home-based instruction visits are scheduled (instructor's availability, child's condition, most wakeful time of day for child, or family schedule/other appointments)?
 - Does the child look forward to home-based instruction?
2. Home-based instructor information
 - How many home-based instructors provide teaching?
 - Does the same instructor(s) teach the student each week?
 - Does the child have a good rapport with the home-based instructor(s)?
 - Does the student work well with the home-based instructor(s)?
3. Supplies
 - Is the child provided with the necessary textbooks/supplies from the school district for home-based instruction?
 - Is the child provided with a list of additional supplies needed for home-based instruction?
 - Are the textbooks used by the home-based instructor the same as those used in the child's classroom?
 - Does the school district have access to Internet communication/virtual classroom/webcam?

4. Strengths and weaknesses of home-based instruction
 - What subjects are being provided through home-based instruction?
 - Does the parent feel that there are other subjects that should be provided? (If so, indicate which ones and why?)
 - Does the parent feel that home-based instruction has helped the child maintain academic progress?
 - Does the parent feel home-based instruction is easier for the child than school?
 - Does the parent feel the child is being challenged to learn with home-based instruction?
 - Does the parent feel that home-based instruction allows the child the opportunity to receive academic instruction specific to your child's needs and learning ability?
 - Does the parent feel home-based instruction limits the child's/your ability to participate in other activities (physical education, art, music, science labs, group projects, or field trips)?
 - Does the parent feel that being in the home versus in a classroom setting/environment has had an impact on learning? If so, in what way?
 - Does the home environment provide for a quiet, comfortable, well-lit setting for school instruction?
5. Expected and actual frequency of home-based instruction
 - Is the parent aware of how many visits/hours have been allocated for your child and over what period of time?
 - Has the child been granted the number of visits/hours allocated? (If not, indicate why.)
6. Record keeping of dates and duration of home-based instructor visits
 - Does the parent keep a record of home visits (dates, times)?
 - Are there forms from the school that the parent must sign before or after home-based instruction sessions?
 - Does the school communicate with the parent how many home visits/hours remain?
7. Ability of home-based instructor to teach all courses
 - Is the home-based instructor from the school district?
 - What grade level/subjects does the home-based instructor teach?
 - Has the home-based instructor provided evidence of qualification to provide instruction on subject matter?
 - Is the home-based instructor an effective teacher (child is able to understand lessons; many methods are used - visual, auditory, use of models, etc.)?
 - Are there language or cultural barriers that would impact learning?
8. Effectiveness of communication between school- and home-based instructor
 - Has the school identified a contact person to communicate with the home-based instructor?
 - Are plans for home-based instruction clearly identified between school district and home instructor (scheduling; subjects)?
 - Does the home-based instructor provide the school with feedback regarding the student's progress and further recommendations?
 - Does the instructor feel that all resources for home-based education are provided by the school district (number of hours for visits)?
9. Access to home-based English Language Learner (ESL/ELL) instruction, if needed
 - Are there language or cultural barriers that would impact learning?
 - Have these issues been addressed with the school district?
 - Have accommodations been made to address these issues?
 - As per the family and instructor, have these accommodations been effective in teaching/learning?
10. Performance on home-based assignments versus school-based assignments
 - Are home-based assignments modeled on classroom-based assignments?
 - In what ways, if any, are home-based assignments modified relative to classroom-based assignments?
 - Is the student given any assistance with completing the assignments? If so, what kind of assistance (open book, family support)?
 - What are the expectations of home-based assignments (complete them all, will they count towards overall grade, assignments will be completed within a certain time frame, and assignments may be reviewed and modified for improved grades)?
 - How does the student perform on given assignments?
 - Do you feel the child's performance is reflective of her academic potential? If not, why?

Key Issues for Monitoring School Instruction and Academic Progress

1. Overall attitude towards school (any concerns warrant further assessment)
 - Does the student generally enjoy being back in school?
 - Has the child established friendships with classmates?
 - Are there problems/concerns with any of the classmates?
 - Are there problems/concerns in any specific class?
 - Does the child appear to be happy about attending and participating in each class?
 - Has the student expressed enthusiasm about any particular class/classes?
 - Has the student expressed disliking any particular class/classes?
2. Teacher(s)' awareness of cancer history
 - Are teachers informed about the student's medical history?
 - Have teachers been told about the physical, cognitive, and emotional/behavioral sequelae of cancer and/or treatment?
 - Are teachers aware of the expected frequency of school absences during what remains of treatment?
3. School attendance
 - Number of missed whole and partial days last week
 - Number of missed whole and partial days over the past month
 - Frequency of tardy arrival to school
 - Frequency of early dismissal
4. Level of academic performance
 - Is the student's performance on par with grade-based expectations?
 - Is the student's performance similar or different from his performance prior to diagnosis?
 - If the student's performance is below grade-level expectations and his own learning trajectory, what factors may be contributing to his difficulties?
 - Disease - or treatment-related impairments (cognitive, visual, auditory, fine and gross motor)
 - Missed instruction or missed learning opportunities (i.e., desk work skills may be deficient in a child who returns to school after missing kindergarten)
 - Premorbid learning or developmental disabilities
 - Psychosocial stressors
5. Formal education plan (e.g., 504 Plan or IEP)
 - Is there a formal educational plan in place?
 - How well is the plan being implemented in each class (ask for concrete examples)?
 - Do the student and family think the plan is adequate and helpful? Why or why not?
6. Course planning
 - Are the student's current courses appropriate given the prior year's level of academic participation and progress?
7. Work load
 - Are assignments manageable in regard to quantity and time required as well as complexity given the student's skills?
 - How many hours per night is homework taking? Are these time demands in line with teacher guidelines and family's expectations?
 - Is the student granted extended time on in-class and out-of-class assignments when needed?
 - Does the student feel caught up or like she is running an unwinnable race?
 - Is a plan in place in each class for tracking and making up missed assignments?
8. Academic help during absences
 - Does the family notify teachers of anticipated absences ahead of time?
 - Is there an effective plan in place for getting academic help when the student misses school?
 - Does the student promptly get missed class notes, important in-class and homework assignments?
 - Is the student and/or family able to communicate with her teacher(s) in a timely fashion when absent?
 - Does the school post work assignments on the internet/web page? If so, does the student have access to the internet/web page?

9. Somatic complaints

- Does the student experience headaches, stomachaches or other symptoms before, during or after school?
- How often does the student visit the school nurse?

10. Fatigue

- Is the student falling asleep in class or in the nurse's office?
- Is the student taking a nap in the afternoon or early evening?
- Does the student get adequate sleep?
- Does the student have adequate sleep patterns?

11. Books and materials

- Does the student have a second set of textbooks at home?
- Does the student have access to a convenient locker or cubby?
- For a student with fatigue and weakness, is there a manageable plan in place to minimize toting materials from class to class (i.e., may leave books in classroom)?

12. Recess/Physical Education participation

- Is the student cleared to participate?
- If yes, is the student participating as appropriate and enjoying it?
- If not, does the student enjoy the alternative activities he/she is permitted to do during these periods of the school day?

13. Re-establishment of social connections

- How often is the student contacting and seeing friends outside of school?
- Are friends generally reciprocating these interactions?
- Is the student getting together with friends more or less than prior to diagnosis?
- Is the child generally satisfied with his social support and interactions?
- Are there any concerns about bullying or teasing?

Points for Discussion as Student Approaches School Re-entry

During the time of transition back into regular school attendance, the school liaison will meet with the family and child to discuss academic progress and instructional services. Topics for discussion include: retention, social re-integration and adjustment, advocacy skills and training, and neuropsychological testing for treatment-related late effects. Often these topics are best addressed first with family/parents and then, as appropriate, with the child, with consideration given to her age, developmental status, and particular circumstances.

Retention

Grade retention is an idea often dismissed by parents, children and teachers alike. However, for some children, the opportunity to experience a grade more completely can be socially and academically life-saving, especially when attendance the previous year was minimal due to treatment. Repeating a year of school instruction that was largely done at home and/or in the hospital during treatment may ensure adequate preparation for what lies ahead academically. This may be particularly true if there is a transition to a new school in the near future (i.e., elementary to middle school, middle school to high school, or high school to college). For some children, failing to repeat a grade may leave them with large gaps in their academic and classroom-based skills and may set them up for long-term academic difficulty. Hence, the option of retention is important to discuss with families. Decisions should be made on an individualized basis in light of the family's knowledge of their child's academic, emotional, and behavioral strengths and weaknesses as well as the quality of the home-based and hospital-based instruction of the previous year.

Key Points to Cover Regarding Retention

1. Individualized decision
2. Not always a bad idea/may be a reasonable recommendation
3. Some considerations:
 - Socialization – consider social costs of repeating vs. social readiness for next grade
 - Is this an important transition year? – elementary, middle, high school
 - Consider child’s personal strengths and weaknesses
 - Consider the quality of home-based instruction services child received and his/her resulting academic readiness

Social Re-integration and Adjustment

For many children, the process of re-establishing connections with friends and classmates takes longer than they hoped and expected. Children need to regain their self-esteem, confidence, and identity following the diagnosis of cancer. School intervention programs are wonderful resources that help facilitate and promote social re-integration. It is important to encourage families to be patient with the process and to take steps to create opportunities for the child to interact with peers. In addition to connecting with peers in their home community, many teens enjoy and benefit from accessing the social networking websites available for adolescents with cancer and other medical conditions. Participation in cancer survivorship camps as well as traditional camps and extracurricular organizations can provide easily accessible opportunities to meet new friends, practice and develop social skills, and receive social support.

Key Points to Cover Regarding Psychosocial Adjustment

1. Suggest websites designed for teen cancer survivors and healthy adolescents
2. Encourage participation in camp experiences
3. Encourage peer interactions through participation in sports, school clubs, and service projects
4. Encourage taking up a hobby
5. Help anticipate the ways in which expectations for behavior may be changing at home as the family defines a “new normal” following treatment

Advocacy Skills

Educating and empowering families to advocate for their children’s educational needs begins at the time of diagnosis. Collaboration with the liaison promotes a comprehensive approach to addressing school-related issues. Following re-entry and during periods of intensive treatment, parents are the voice advocating for their children with special needs in the school setting. There are a variety of ways to encourage parents’ advocacy skills; site-specific resources are a factor to consider.

Key Sources for Teaching Advocacy Skills

1. Suggest a parent-support group to provide advocacy training
2. Provide copies of the special education laws and patient rights and explain how these are applicable to the childhood cancer population (<http://www.wrightslaw.com>)
3. Assist parents in obtaining free books from the American Childhood Cancer Organization (<http://www.acco.org>) that address educational issues for children with cancer
4. Offer periodic workshops for families to address educational issues, such as school re-entry, neuropsychological testing for cancer survivors, and/or advocating for your child in 504/IEP meetings

Neuropsychological/Psycho-educational testing

Children who receive treatment targeted directly at the central nervous system (i.e., cranial radiation, intrathecal chemotherapy) are at risk of developing neurocognitive late effects, or deficits in thinking and learning that result from exposure to neurotoxic agents. If resources are available for testing, a baseline assessment at the end of treatment for patients who received neurotoxic treatment is recommended. Current guidelines published by the Children's Oncology Group recommend that all childhood cancer survivors at risk for neurocognitive late effects have a baseline evaluation at the time of entry into long-term follow-up. Such evaluations include an assessment of intelligence, academic achievement, attention, memory, processing speed, visual-perceptual skills, and executive functioning. An evaluation of this kind provides schools and families with a starting point to begin monitoring patients for emerging neurocognitive late effects and to mark academic progress. Despite this recommendation, many insurance providers do not cover this service; therefore, it may be helpful for the liaison to advocate that the school system perform an evaluation of the child. While the results of school-based testing can be helpful and informative for the individualized education plan (IEP), subtle late effects may be missed in an evaluation of this kind. For this reason, it will be helpful for the liaison to educate school personnel about the specific late effects that each patient is at risk of developing.

Key Points for Discussion about Testing

1. Testing is recommended for all patients who received neurotoxic therapy
2. Baseline testing is not always covered by insurance
3. Liaison may advocate for testing to be performed by school
4. Liaison educates schools about risk of late effects based on treatment exposure
5. Late effects may be progressive yet delayed in onset, therefore re-evaluation is often recommended every 2-3 years

Chapter 4

Ready, Set, Go . . . School Reentry: Faculty and Classroom Presentations

The return to school is the child's hope for the future. It promotes learning, normal psychosocial development, and a sense of purpose. During the school re-entry process parents, children, and teachers may face challenges. Barriers for parents include feeling the need to protect the child, feeling overwhelmed by medical demands (caregiver burden), lack of educational resources in the local school district, and inconsistent school policies. Barriers for the child include separation anxiety, effects of the medical condition, changes in body image, loss of control, and social isolation. Barriers for the teacher include fear, lack of medical knowledge, personal experience with cancer, uncertainty of her role in relation to the sick child, limited funding and/or lack of resources, and classmates' and parents' possible negative reactions to the sick student. In collaborating with school personnel and families, the liaison helps to break through and move beyond these barriers by dispelling myths, alleviating concerns, and providing resources.

When the child is medically cleared to return to the school setting, a faculty meeting is essential to facilitate a smooth transition. The liaison, along with the child's medical team, family, and school personnel, must consider several factors that determine a child's readiness to return to school. Such factors include the child's immune status, strength/physical endurance, fatigue, and pain, as well as fear, anxiety, and willingness to return to school. Other factors include intensity, frequency, and duration and type of treatment (chemotherapy, radiation, surgery) as these may impact school attendance. The goal of school re-entry visits is to provide information about the child's diagnosis, treatment, and side effects to faculty and classmates.

The school liaison collaborates with school personnel to create a comfortable environment for the patient, his schoolmates, the staff, and the school community upon the child's return to the classroom. Prior to the meeting date, it is advisable to discuss the re-entry process with the patient and family. An in depth discussion should explore the child's and family's concerns, fears, and expectations for returning to school. Topics to be discussed and materials to be presented at the meeting should also be reviewed.

A successful faculty meeting starts with an introduction of those present, clarification of their respective roles, and an explanation of the purpose of the meeting. The philosophy that pediatric hematology and oncology patients belong in school when appropriate should be emphasized. A brief overview of childhood cancer or hematologic disorders should be provided as well as the diagnosis specific to the child. At the faculty meeting, it is recommended that the liaison organize and highlight topics from three main categories: medical, psychosocial, and educational. (Chapter 6 will address the educational needs for children with hematologic disorders.)

Following is a list of individuals who may be included at the faculty meeting.

School Intervention Team Members at Faculty Meeting

1. Hospital staff
 - Education liaison
 - Hospital-based instructor
 - Child life specialist
 - Nurse/nurse practitioner
 - Physician
 - Psychologist
 - Social worker

2. Family
 - Parents/guardians
 - Child, depending upon age and request
 - Other family support, i.e. translator, advocate
 - Home health nurses
3. School staff
 - Teacher(s)
 - School nurse
 - Principal/administrator
 - School psychologist
 - School social worker
 - Guidance counselor
 - Para-professionals (aides, monitors, etc.)
 - Home-based instructor
 - Educational advocate
 - Special education/504 coordinator
 - Physical therapist
 - Occupational therapist
 - Speech therapist

The following is a suggested outline of topics to be addressed during the faculty meeting.

Content Discussed at Faculty Meeting

1. Medical topics
 - Diagnosis
 - Treatment plan (e.g., chemotherapy, radiation, surgery and/or bone marrow transplant)
 - Duration of treatment
 - Medications
 - Physical, Occupational, and Speech therapies and other supportive services
 - Side effects of disease and treatment (acute and long term)
 - Risks of infections
 - Medical devices/central lines
 - Restrictions/modifications
 - Prognosis, relapse, and death
2. Psychosocial topics
 - Emotional impact and psychological adjustment
 - Body image
 - Peer relations
 - Child's understanding of illness
 - Developmental issues
 - Family and sibling support
 - Treatment experience
 - Coping strategies
 - Cultural and religious considerations
 - Social skills training
3. Educational topics
 - Acute educational issues
 - Long term educational issues
 - General accommodations, 504, IEPs
 - Promoting school success

The following checklists may be helpful to review prior to a faculty meeting. These include much, but not all, of the specific content that is commonly addressed at a school faculty meeting. The liaison should review this checklist with the child's treatment team prior to the faculty meeting to determine which topics are relevant and how they should be addressed at school for each individual child.

Medical topics

- ☐ Simple biology of disease/affected organs
- ☐ Relevant medical terminology
- ☐ Teaching doll
- ☐ Chickenpox and other communicable diseases
- ☐ Cancer is not contagious
- ☐ Treatment choices
- ☐ Ports or catheters, PICC, shunts
- ☐ Feeding tubes
- ☐ Physical changes
- ☐ Delays in growth and physical development
- ☐ Physical appearance
- ☐ Nausea
- ☐ Fatigue
- ☐ Mouth sores
- ☐ Hair loss
- ☐ "Puffiness" from steroids
- ☐ Unexpected side effects
- ☐ Wheelchairs or crutches
- ☐ Amputation, prostheses
- ☐ Hydration, snacks
- ☐ Bathroom breaks
- ☐ Permission to visit nurse
- ☐ Sun safety

Psychosocial topics

- ☐ Dispelling myths about hospital and illness
- ☐ Impact of illness and treatment on developmental stages
- ☐ Fear
- ☐ Anxiety
- ☐ Social stigma
- ☐ Effects of isolation
- ☐ Value of normalcy
- ☐ Value of school
- ☐ Connectedness to peers via school
- ☐ Fashion changes during absence
- ☐ Keeping current with kid/teen culture/trends
- ☐ Suggested coping strategies
- ☐ Siblings in same school
- ☐ Discuss need to educate peers and encourage peer support group

Educational topics

- ☐ Anticipate intermittent attendance
- ☐ Discuss modified day/adjusted schedule
- ☐ Address academic worries
- ☐ Offer modified physical education (P.E.) activities if necessary
- ☐ Select course work in areas of strength
- ☐ Review student's academic performance level prior to illness
- ☐ Expect student to pursue higher education
- ☐ Offer second set of textbooks to keep at home
- ☐ Allow extra time to travel between classes
- ☐ Offer use of elevator key
- ☐ Consider classroom seating preference
- ☐ Discuss potential for neurocognitive late effects of treatment if relevant
 - Processing speed deficits
 - Memory and attention impairments
 - Planning and organization skill impairments
 - Delays or impairments in fine and gross motor skills
 - Handwriting difficulties
 - Possible decline in overall IQ reflecting not a loss of previous skills, but a falling off of student's pre-illness developmental trajectory
- ☐ Discuss need for neuropsychological and/or psycho-educational testing
- ☐ Consider the appropriateness of academic accommodations for the student
 - Simplified instructions and/or written instructions for assignments
 - Computer-printed notes, assignments and homework
 - Providing the student with guided notes to complete or a classmate's or teacher's lecture notes
 - Teaching the student to use a color-coded organizational system
 - Use of a calculator, Personal Digital Assistant (PDA), laptop computer
 - Use of other assistive technology (FM trainer, SMART Board™)
 - Extended time on tests and assignments
 - An aide to take notes for visually or hearing impaired students
 - Reduced workload with an emphasis on mastery
 - Use of multi-sensory methods of teaching
 - Teaching the student specific learning strategies, study and time management skills
- ☐ Evaluate need and provide supportive services (e.g., OT, PT, and speech therapy)

After the faculty meeting, it is important to meet with the student's classmates to further promote a smooth transition and address the needs of the child as well as his classmates. A discussion must be held with the parent and child regarding the content of the classroom visit as well as potential questions from classmates that may arise. It is important to prepare the child to handle teasing. Having an explicit discussion about ignoring comments, rehearsing simple statements with the student, encouraging the student to walk away, and helping him identify a supportive contact person at the school are all important means of preparing the student to return to the classroom. It is also good practice to discuss the content of the presentation with the teacher prior to the visit.

The classroom visit fosters character building, health education, and cancer prevention, while answering questions in an age and developmentally appropriate manner. The presenters should address any misconceptions or myths that the classmates may have (for example, that cancer is contagious or that their classmate deserved it or did something to cause it). The medical and psychosocial aspects of cancer are important concepts to discuss at the classroom visit. The medical aspects include an overview of cancer, its treatment and side effects, and other procedures with which the student's classmates are unlikely to be familiar. The psychosocial aspects include encouraging classmates to be empathetic and supportive, explaining how to be a friend (not to treat the child differently) and offering suggestions on what they can do to assist the child. The classroom presentations include fun, interactive question and answer sessions incorporating themes of courage, bravery and heroism.

A classroom visit is generally intended for elementary school students. In certain instances, a classroom presentation is appropriate in the middle and high school settings, where there is a core group of classmates with whom the child spends his day. In rare instances, it may be appropriate for a particular classmate to be excused from the classroom presentation, and be addressed privately.

A classroom visit starts with an introduction of all present and their roles. It is helpful to establish the knowledge base of the classmates related to overall healthcare, cancer and blood disorders, their classmate's experience, and the reason for the presentation. This helps to focus the information that will be presented to the class, as well as to dispel any misconceptions about the child.

The role of the child during the classroom presentation will vary from individual to individual depending upon the comfort level. This may range from simple observation, to active participation as an "expert" regarding their illness and experience. The opportunity for the patient to participate at their desired level serves to empower the child.

Following is a list of individuals who may be included at the classroom visit.

School Intervention Team Members at Classroom Visit

1. Hospital staff
 - Education liaison
 - Hospital-based instructor
 - Child life specialist
 - Social worker
 - Psychologist
 - Nurse/nurse practitioner
2. Family
 - Patient, as desired
 - Parent
3. School staff
 - Teacher(s)
 - Principal/administrators
 - School nurse
 - Counselor
 - Social worker

The following is a suggested list of topics to be addressed and teaching tools that are helpful in facilitating the classroom visit.

Classroom Visit

1. Medical topics
 - Diagnosis
 - Not contagious
 - Not the child's fault
 - Rare/Incidence
 - Pediatric vs. adult illnesses
 - Treatment
 - Types of treatment
 - Medications and routes of administration
 - Duration and frequency
 - Side effects of treatment
 - Visible versus not visible
 - Long-term versus short-term

2. Psychosocial topics

- Promote peer acceptance
- Teach the importance of “normal” treatment
- Suggest strategies for interventions by peers
- Encourage teamwork
- Offer character building lessons
- Provide emotional support

3. Teaching tools

- Medical teaching dolls/puppets
- Books
- Videos
- Individualized PowerPoint® presentations
- Photographs and drawings
- Innovative, homemade supplies (such as “blood soup”, clay models) made with readily available and inexpensive materials

The following checklist may be helpful prior to a classroom visit. It includes much, but not all, of the specific content that is commonly addressed during a classroom visit.

Classroom Visit Topics

- ☐ Describe options for child’s involvement, if desired (showing port, leading discussion, answering questions, and handing out materials)
- ☐ Prepare patient to answer questions from other students
- ☐ Explain basic anatomy and biology: normal and disease
- ☐ Use age appropriate medical terminology
- ☐ Provide realistic and honest information, yet avoid “doom & gloom”
- ☐ Dispel myths (e.g., illness is punishment, cancer is contagious)
- ☐ Describe hospital experience
- ☐ Promote empathy. “How do you feel when you are sick?”
- ☐ Use teaching tools (e.g., books, videos, puppets, and photos)
- ☐ Explain ports, catheters, and shunts
- ☐ Describe wheelchairs or crutches
- ☐ Clarify permission for frequent drinks and snacks
- ☐ Clarify permission for frequent breaks/bathroom visits
- ☐ Explain changes in appearance (e.g., hair loss, weight gain/loss, puffiness from steroids)
- ☐ Describe temporary and long-term changes in physical ability (e.g., fatigue, motor skills, hearing, and vision)
- ☐ Discuss social stigma
- ☐ Encourage connectedness to peers; avoid isolation
- ☐ Discuss importance of “how to be a friend”
- ☐ Share examples of what friends can do: cards, calls, text messages, e-mail, and instant messages
- ☐ Discourage treating patient differently
- ☐ Discourage teasing
- ☐ Recommend buddy system
- ☐ Educate students about illness prevention
- ☐ Address possibility of death, as appropriate
- ☐ Recognize patient’s courage and hard work (e.g., bravery badge, hero coloring sheet, and verbal praise)
- ☐ Discuss teamwork toward a smooth transition

Chapter 5

Moving Forward . . . Childhood Cancer Survivorship: Educational Issues and Cognitive Late Effects

The good news about childhood cancer is that more and more children are surviving this disease and returning to school. However, many families are surprised to learn that although therapy has ended, the sequelae of the disease and its treatment are ongoing. The liaison plays a critical role in guiding the student and his family through this potentially anxiety-inducing time by helping them navigate the landscape of cancer late effects and the impact these can have on the educational experience.

Late effects of cancer refer to problems that arise from the disease or its treatment: difficulties that develop or persist after therapy is completed. Late effects generally fall into three categories: physical, emotional, and neurocognitive. Examples of common physical late effects include endocrine dysfunction (including fertility problems), diminished pulmonary function, abnormal cardiac function, peripheral neuropathy (i.e., numbness and/or tingling in the hands or feet), vision and hearing loss, fine and gross motor deficits, and chronic fatigue. These persistent late effects can be a constant reminder of the stresses associated with treatment, and may also prompt fears about the potential for relapse, both of which can impact the emotional functioning of survivors. While the majority of cancer survivors cope well following their cancer experience, they can develop anxiety, depression, and post-traumatic stress disorder even years after cancer treatment ends, and they should receive interventions to alleviate this distress. Additionally, children who undergo a lengthy treatment course are likely to miss a significant amount of school and also miss out on developmentally appropriate social opportunities with their peers. These children may struggle socially and can benefit from counseling and social skills training within the school or in a community based setting.

Students who have survived cancers involving the central nervous system (i.e., brain and/or spinal cord) or who have received therapy that is toxic to the developing brain are at risk for developing neurocognitive late effects. Neurocognitive late effects can be described as difficulty with aspects of thinking, learning, problem-solving, processing and organizing information, remembering, paying attention, and concentrating; all of which can impact academic functioning. The liaison recognizes factors that place childhood cancer survivors at higher risk for educational problems, utilizes assessment and screening methods for identifying children at risk, and recommends appropriate interventions for children experiencing educational problems.

Not all survivors of childhood cancer experience academic difficulties following treatment. Because specific treatment modalities and experiences during cancer treatment are known to place students at greater risk for experiencing academic problems, a risk-adapted model should be used to identify students at increased risk for developing school-related problems following treatment. The list below outlines the factors that increase a student's risk for developing educational difficulties.

Risk Factors for Educational Difficulties

- *Diagnosis* – Diagnoses of leukemia, Non-Hodgkin lymphoma, high-risk neuroblastoma, tumors of the brain or spinal cord, and tumors of the eye, head, or facial area
- *Treatment* – Treatment that includes intrathecal chemotherapy, high-dose methotrexate, high-dose and/or chronic corticosteroid use, irradiation to the head or neck (including whole brain radiation or total body radiation), and stem cell transplantation
- *Age at diagnosis* – Children who were treated for cancer at a young age (during infancy, toddler, or pre-school years)
- *Gender* – Girls are at greater risk than boys although the reasons for this are not well understood in the late-effects research literature
- *Pre-morbid functioning* – students with a history of cognitive, academic, and/or social-emotional problems prior to their cancer diagnosis and students with a history of inconsistent school attendance prior to their cancer diagnosis
- *Family history* – A family history of learning/attention/behavior disorder, particularly among parents or siblings

- *Sensory or physical impairment* – Persistent issues related to fatigue, weakness, limited mobility, seizure disorder, etc., may present a barrier to a student's accessing or benefiting from formal educational experiences
- *Chronic illness* – Chronic health problems that result in repeated school absences, extended hospitalizations, or the need for ongoing academic tutoring
- *Transitions* – Students who are unable to attend school during important transition years, such as kindergarten or the first year of middle school or high school, may develop academic difficulties as a result of their relative lack of preparation for these significant transitions
- *Academic instruction during treatment* – Students who were unable to attend school regularly or who were too sick to participate actively in home-based instruction may be at increased risk
- *School re-entry process* – Students who experienced a difficult school re-entry or who had excessive absences following the transition back to full-time school attendance may be at increased risk
- *Barriers to services* – Geographic, financial, language, or cultural barriers to accessing and/or benefiting from formal educational services should be considered

Students who have completed cancer treatment may or may not have had formal neuropsychological or psycho-educational testing. Many treatment centers perform formal assessments before, during, and after treatment for students who have received high-risk therapies. If testing has not been done previously, it is recommended that the liaison refer all high-risk students for a baseline evaluation at the time of entry into long-term follow-up care, even in the absence of overt symptoms of neurocognitive late effects. It should be noted, however, that it might be difficult to obtain insurance authorizations for testing in circumstances where the student is not yet demonstrating any clinical symptoms. Similarly, psycho-educational testing may not be provided by school systems until a student is demonstrating academic failure or inability to perform at grade level.

Students who report difficulty with memory, attention and concentration, keeping up with fast-paced conversation or work-demands, or who experience academic problems for the first time should be referred for formal testing, regardless of cancer diagnosis or treatment. It may be helpful for the liaison to consider that even students who have not received high-risk therapies may require testing due to factors such as prolonged school absences or difficult school re-entry. Testing should be repeated every 2-3 years until the student has completed his formal education. Cognitive late effects may become more apparent over time as higher-level cognitive abilities are required to manage more challenging academic and organizational tasks at advancing grade levels. It is recommended that the liaison refer the student for re-evaluation at important transition points (e.g., middle school to high school, or high school to college) or when new problems emerge. Increased consultation to families and schools during these critical transition periods is also recommended.

A primary role of the liaison during the long-term follow-up period is the continued monitoring of a student's academic progress through interview, review of school documents, annual assessments, and educational rating scales results. Many of the issues highlighted in Chapter 3 are important for monitoring a student's academic progress during treatment and are also relevant in monitoring a student's progress once therapy has ended. Below are helpful tips for obtaining information that the liaison can share with the medical team and the school to inform them of the student's progress and to develop an educational plan.

Assessment and Screening

1. Initial educational intake interview

- *Assessment of pre-diagnosis functioning* – Perform an educational intake interview to review the student's educational and developmental history, including a personal and family history of cognitive, academic, or social-emotional problems. Ideally, this information is gathered at the time of diagnosis and is used to inform school planning during treatment; however, this information can be gathered at any point during or following treatment.
- *Assessment of current school functioning* – Specific questions about courses and academic performance, including an assessment of the amount of effort required for school performance, should be included. It is important to assess this information on an annual basis because the onset of neurocognitive late effects and consequent academic problems may be delayed or progressive. In this way, academic problems that were not evident previously may become evident during subsequent years.

2. Review of school and/or therapy documents
 - Review Response to Intervention (RTI) and curriculum-based assessments that may have been performed by the school. These are assessments that would have been performed at the child's school as part of regular monitoring of all students' academic progress. If available, any existing IEP and/or 504 documents, including any school based eligibility assessments and current report cards should be reviewed as well.
 - Review Physical/Occupational/Speech assessments, audiology reports, vision assessments, orientation/mobility assessments, assistive technology evaluations, and treatment progress notes if these are available. These often include helpful recommendations to guide students' educational plans.
3. Annual follow-up assessment
 - It will be important to assess the following areas on an annual basis, perhaps in conjunction with the student's annual medical appointment
 - Evaluate the family's and student's understanding of student's continued risk status and knowledge of warning signs of neurocognitive late effects
 - Review previous school accommodations, supports and services including how appropriate the parent and student think the accommodations are and how faithfully the accommodations are being implemented
 - Revise school contact information and update authorization to communicate with the school as needed
 - Assess the family's/student's compliance with recommended follow-up services and medical intervention (e.g., neurocognitive assessment, Endocrinology, Neurology, Physical and/or Occupational Therapy intervention, mental health counseling, and tutoring services)
 - Review the student's school attendance history since last appointment
4. Rating scales
 - Where possible, the use of developmentally appropriate, empirically validated assessment tools are recommended to gather data about school, behavioral and social-emotional functioning, and quality of life. It is helpful to get as many perspectives as possible, including that of parents, teachers, and students themselves. Several instruments with collateral parent-report, teacher-report and self-report formats are available commercially.

The liaison should be aware of the various recommended interventions, accommodations, and services for childhood cancer survivors intended to promote school success in this population. These recommendations address academic, physical, and psychosocial functioning. Most are relevant for students of all ages, although there are some specific recommendations for students of particular ages, for example students attending preschool or college. It should be noted that while each of these recommended interventions is intended to address or accommodate areas of possible weakness or dysfunction following cancer treatment, research to document the effectiveness of these strategies in childhood cancer survivors is ongoing.

Below are recommendations the liaison may consider to address academic issues for students.

Academic/Cognitive Functioning

1. For parents
 - Explain education laws, rights, and the range of remedial and other services that may be available through the school system (these will vary from one school district to another)
 - Explain parents' right to request an IEP (or other) meeting any time the child's needs change
 - Discuss specifically their right to bring an advocate to all school meetings, and highlight the benefits of having an additional person attend all school meetings, especially IEP and 504 meetings
 - Help parents develop a notebook to keep track of school documents, including 504 Plans, IEP's, teacher notes, meeting notes, and neurocognitive testing reports

2. For schools
 - Consider making initial contact with the school's principal and special education director who can then designate the most appropriate contact person at the school (i.e., guidance counselor, school nurse) for future contacts. Identify a designated hospital-school liaison to facilitate communication between the treating facility and the student's school
 - Evaluate the school's knowledge of the student's medical history, their understanding of the student's continued risk status, and their knowledge of warning signs of cognitive late effects, emphasizing that cognitive late effects may be delayed in onset and progressive in nature
3. For students
 - All childhood cancer survivors qualify for intervention or accommodation under either *The Individuals with Disabilities Education Act* (IDEA) or *The Rehabilitation Act of 1973-Section 504*. All students who have been treated for cancer should be referred for services under one of these laws. Most commonly, students will be eligible for IDEA under the "other health impaired" category, and they will be entitled to receive Special Education services through an Individualized Education Plan (IEP). If the student does not meet IDEA eligibility, Section 504 accommodations should be considered.

Below are recommendations the liaison may consider to address physical limitations for students.

Physical Functioning

1. For students of all ages
 - Refer for speech-language therapy to address a delay or possible disorder
 - Refer for physical and/or occupational therapy services to address fine or gross motor impairments and mobility limitations
 - Refer for vision orientation/mobility services if needed. It is likely that a referral to audiology or ophthalmology will be required if a more comprehensive assessment is needed
 - Consider requesting assistive technology for students with significant physical impairments (e.g., voice-recognition software for students with significant fine motor impairments)
 - Consider requesting adaptive physical education (APE) classes for students with significant motor impairments or modified PE requirements for students with less extensive limitations (i.e., students with fatigue, chronic pain, or shortness of breath)
2. For middle school and high school students
 - Students may need a parking spot or locker that is close to classrooms in order to minimize travel between classes or from the parking lot into the school building
 - Students with motor impairments may need additional time to travel from class to class or may need approval to use the elevator instead of the stairs (hall pass)
3. For college students
 - Students may need a parking spot or dormitory that is close to classroom buildings or may need to request a dormitory with an elevator
 - Students and their advisors may need to consider the student's limited mobility when planning the student's class schedule, for example to limit the need to travel from one building to another in a short period of time
4. For post-secondary students (vocational training, independent living)
 - Consider motor and sensory impairments when evaluating appropriate job training opportunities

Below are recommendations the liaison may consider to address the psychosocial needs of students.

Psychosocial Functioning

1. Monitor students for signs of anxiety, depression, or social problems
2. Refer to school guidance counselor or school social worker if concerns about emotional, behavioral or social functioning are noted
3. Identify "safe" place or person at school to go to when feeling overwhelmed

4. Refer to community mental health resources if indicated
5. Refer for social skills training intervention if indicated
6. Refer to support group for cancer survivors (online or in-person)
7. Refer to Life Skills group
8. Encourage participation in non-academic activities such as sports, theater, music, chess, service organizations, or volunteering which the student enjoys and through which he or she can experience success
9. Recommend camp opportunities for survivors, either as camper or counselor/mentor

The following checklist of classroom accommodations may be helpful to review prior to a faculty meeting. While not all of these accommodations will be relevant for every child who has been treated for cancer, some specific accommodations will be beneficial.

Classroom Accommodations

- ☐ Request remedial academic services to address missed academic instruction. Areas of needed instruction can be identified through individual neuropsychological or psycho-educational assessment, state standardized testing, or curriculum-based assessment
- ☐ Request allowable accommodations for state standardized testing if the student meets criteria
- ☐ Request accommodations for attention and memory impairment if this need is identified for the student
- ☐ Request accommodations for fine motor weakness if this need has been identified
- ☐ Request an extra set of books for the student to keep at home so that these are accessible during unexpected absences
- ☐ Consider oral testing to accommodate fine motor weakness and/or difficulties with processing speed and written expression if these have been identified
- ☐ Consider extended time on tests and assignments to accommodate slow processing speed and/or reading difficulty
- ☐ Emphasize work quality over quantity employing a guideline of assigning a workload that promotes mastery without overwhelming the student
- ☐ Explore the local availability of cognitive remediation programs
- ☐ Regularly review the suitability and implementation of accommodations in the classroom, whether these are provided through an IEP or a 504 Plan
- ☐ Explicitly teach study and organizational strategies, for example, time management skills, use of agendas, checklists, notebooks, and color-coding strategies
- ☐ Explicitly teach memory strategies, such as the use of mnemonics or visualizations strategies
- ☐ Explicitly teach note-taking strategies and consider training in the use of technology, such as Pulse™ Smartpen or voice-recognition software for note-taking
- ☐ Consider providing teacher-prepared notes to the student, for example PowerPoint® slides or outlines
- ☐ As an alternative, the student can be provided notes from a reliable peer
- ☐ Identify a study buddy or staff member (not the sibling) who can help student make sure she has all necessary books and materials to take home at the end of the day
- ☐ Help the student identify appropriate homework behaviors; for example, determine the best time of day to study, the best physical location to do homework, and work together to put a reasonable time limit on homework
- ☐ Refer the student for accommodations on state standardized tests and on the SAT and ACT. Note that formal testing will be required to qualify for accommodations on the SAT and ACT, as well as documentation that similar accommodations have been *used*, not just made available, in the classroom
- ☐ Begin teaching the student to advocate for their academic needs on their own. In most cases it will be appropriate for the student to begin attending IEP and other school meetings once the student begins high school
- ☐ Request that a "transition plan" be developed to plan for post-secondary education, whether that is college or vocational training. This transition plan should be part of the student's IEP beginning in high school
- ☐ Consider use of a laptop computer or iPad for note taking
- ☐ Consider a different type of lock on the locker of a student with fine motor or visual impairment

Below is a checklist of recommendations for pre-school age students, college students, and students in other post-secondary educational setting.

Specific Recommendations for Preschool-Age Students

- ☐ Refer student to state-funded Early Intervention Services for children from birth to 3 years of age
- ☐ Refer student to the local school district for preschool services (e.g., Head Start or other Pre-Kindergarten services, OT/PT/Speech services) after 3 years old. Student may need to be certified as a Special Education student (generally under the category of "other health impaired") to qualify for some services

Specific Recommendations for College Students

- ☐ Provide information about college scholarships available to childhood cancer survivors. Note that this information changes frequently and needs to be updated often
- ☐ Provide a summary of the student's cancer treatment for the student to take to college, and make sure the student is aware of the local medical and mental health facilities where she will be attending school
- ☐ Make sure student is aware that she needs to contact Office of Student Disability (this may have a different name at different institutions) at the college or university to request academic accommodations. It is often helpful to inquire about the level of assistance offered at each college or university during the application process, as this will vary significantly from one setting to another

Specific Recommendations for Other Post-Secondary Students (vocational training, independent living)

- ☐ Refer for vocational rehabilitation and/or job training services if this has not been done previously. Cognitive, physical and sensory impairments should be considered when evaluating job training requirements
- ☐ Request that the vocational counselor be involved with the student in a proactive manner to inform employers of the survivor's strengths and weakness rather than postponing involvement until a problem has occurred on the job

Chapter 6

Obstacles and Hurdles: An Intervention Program Assisting Students with Blood Disorders

School Intervention Programs can be modeled to assist children with various types of chronic illnesses. For this reason, many of the previously discussed recommendations are repeated in this chapter. It is important for the liaison to recognize the individual needs of the children so that she can facilitate educational planning. While children diagnosed with chronic blood disorders face similar challenges in the school setting as children diagnosed with cancer, they may face unique obstacles and hurdles. The school intervention liaison is most likely to assist children with chronic blood disorders which include but are not limited to sickle cell disease, thalassemia, aplastic anemia, bone marrow failure syndromes, idiopathic thrombocytopenic purpura (ITP), Gaucher Disease, hemolytic disorders, bleeding disorders, and other autoimmune disorders. These children often deal with anemia, fatigue, pain, infections, bleeding, and organ dysfunction (e.g. cardiac, pulmonary, renal, and musculo-skeletal). They may also develop serious neurological complications such as stroke, encephalopathy, intracranial hemorrhage, and visual and hearing impairments. The symptoms of these disorders may be episodic or chronic, severe, and incapacitating, resulting in repeated clinic visits or hospitalizations. As a result, this may lead to frequent absences, poor school performance, disruptive behavior, separation and isolation from peer group, anxiety, sense of hopelessness, and/or poor self-esteem. These children face living with the complications of long-term therapy, the challenges of declining health, and the stress of a chronic incurable disease.

The school liaison helps guide children with chronic blood disorders and their families in the school process. The liaison introduces the program and services (as discussed in chapter 2), as well as obtains consent and contacts the school. In meeting with the family, a detailed history should be obtained. It is important to identify the details of the illness, the severity, treatment, and impact on learning, as well as assess whether there are any existing educational services in place (e.g. 504, IEP, PT, OT, or speech). It is also important to assess treatment compliance regarding medications, office visits, and screening tests.

The liaison empowers parents and children by providing them with resources/tools to become their own advocates hoping to improve overall quality of life. Resources include information about the illness, alternative educational/vocational programs, education laws, support groups and social networking, community resources, web sites, and independent living skills. The goal is for the liaison to provide opportunities for parents and children to take ownership of their health care and its impact on their education.

A successful faculty meeting often starts with an introduction of all present at the meeting and their roles. A brief overview of childhood hematologic disorders and school-related issues (educational and social) should be provided. The philosophy that pediatric hematology patients should be in school is important to emphasize during the introduction. It is recommended that the topics discussed during the faculty meeting be organized into three main categories: medical, psychosocial, and educational.

The following is a list of individuals who may be included at the faculty meeting.

School Intervention Team Members at Faculty Meeting

1. Hospital staff
 - Education liaison
 - Hospital-based instructor
 - Child life specialist
 - Nurse/nurse practitioner
 - Physician
 - Psychologist
 - Social worker

2. Family
 - Parents/guardians
 - Child, depending upon age and request
 - Other family support, i.e. translator, advocate
 - Home health nurses
3. School staff
 - Teacher(s)
 - Home-based instructor
 - School nurse
 - Principal/administrator
 - School psychologist
 - School social worker
 - Guidance counselor
 - Para-professionals (aides, monitors, etc.)
 - Educational advocate
 - Special education/504 coordinator
 - Physical therapist
 - Occupational therapist
 - Speech therapist

Following is a list of suggested topics to be addressed during the faculty meeting.

Content Discussed at Faculty Meeting

1. Medical topics
 - Diagnosis
 - Treatment plan (e.g., infusions, transfusions and/or procedures)
 - Duration of treatment
 - Side effects of disease and treatment (acute and long term)
 - Incidence
 - Condition often chronic/life-long
 - Episodic or persistent manifestations
 - Frequency of hospitalizations
 - Risks of infections
 - Medical devices/central lines
 - Pain management
 - Restrictions/modifications/preventive measures
 - Prognosis/disease status
 - Medications
2. Psychosocial topics
 - Emotional impact and psychological adjustment
 - Body image
 - Peer relations
 - Child's understanding of illness
 - Developmental issues
 - Family and sibling issues and support
 - Treatment experience
 - Coping strategies
 - Cultural and religious considerations
 - Social skills training

3. Educational topics

- Acute educational issues
- Long term educational issues
- Accommodations, 504, IEPs
- Promoting school success
- Career/vocational planning

The following checklists may be helpful to review prior to a faculty meeting. These include much, but not all, of the specific content that is commonly addressed at a school faculty meeting. The liaison should review this checklist with the treatment team prior to the faculty meeting to determine which topics are relevant and how they should be addressed at school for each individual child.

Medical Topics

- ☐ Simple biology of disease/affected organ
- ☐ Relevant medical terminology
- ☐ Chickenpox and other communicable diseases
- ☐ Hematologic disease is not contagious
- ☐ Treatment choices
- ☐ Nausea
- ☐ Fatigue
- ☐ Pica
- ☐ Teaching doll
- ☐ Physical changes
- ☐ Delays in growth or physical development
- ☐ Physical appearance
- ☐ Hair loss
- ☐ "Puffiness" from steroids
- ☐ Amputation, prostheses
- ☐ Use of oxygen
- ☐ Ports or catheters, PICC, shunts
- ☐ Feeding tubes
- ☐ Wheelchairs or crutches
- ☐ Unexpected side effects
- ☐ Snacks, hydration
- ☐ Bathroom breaks
- ☐ Permission for unlimited access to visit nurse
- ☐ Transportation/minibus
- ☐ Avoid temperature extremes

Psychosocial Topics

- ☐ Dispelling myths about hospital and illness
- ☐ Impact of illness and treatment on development
- ☐ Fear
- ☐ Anxiety
- ☐ Social stigma
- ☐ Isolation
- ☐ Value of school
- ☐ Value of normalcy
- ☐ Connectedness to peers via school
- ☐ Fashion changes during absences
- ☐ Keeping current with kid/teen culture/trends
- ☐ Suggested coping strategies
- ☐ Siblings in same school
- ☐ Educate peers and encourage peer support group

Educational Topics

- ☐ Anticipate intermittent attendance
- ☐ Discuss modified day/adjusted schedule
- ☐ Address academic worries
- ☐ Offer modified physical education (P.E.) activities if necessary
- ☐ Select course work in areas of strength
- ☐ Review student's academic performance level prior to illness
- ☐ Expect student to pursue higher education
- ☐ Offer second set of books to keep at home
- ☐ Allow extra time to travel between classes
- ☐ Offer use of elevator key or pass
- ☐ Consider classroom seating preference
- ☐ Provide a seat away from windows, doors and cold drafts in classrooms
- ☐ Describe potential neurocognitive late effects of disease
 - Processing speed deficits
 - Memory and attention impairments
 - Planning and organizational skill impairments
 - Delays or impairments in fine and gross motor skills
 - Handwriting difficulties
 - Possible decline in overall IQ reflecting not a loss of previously acquired skills, but rather a falling off of student's pre-illness developmental trajectory
- ☐ Discuss need for neuropsychological and/or psycho-educational testing

- ❑ Consider the appropriateness of academic accommodations for the student
 - Simplified instructions and/or written instructions for assignments
 - Computer-printed notes, assignments and homework
 - Providing the student with guided notes to complete or a classmate's or teacher's lecture notes
 - Teaching the student to use a color-coded organizational system
 - Use of a calculator, Personal Digital Assistant (PDA), laptop computer
 - Use of other assistive technology (FM trainer, SMART Board™)
 - Extended time on tests and assignments
 - An aide to take notes for visually or hearing impaired students
 - Reduced workload with an emphasis on demonstrating mastery
 - Use of multi-sensory methods of teaching
 - Teaching the student specific learning strategies, study and time management skills
 - Access to online coursework and/or online classes so that studies can continue even during periods of illness-related absences
- ❑ Provide cognitive remediation training if needed and available
- ❑ Recommend small group instruction
- ❑ Evaluate and provide supportive services (e.g. OT, PT, speech therapy)

After meeting with the faculty and staff, it is important to meet with the student's classmates to further promote a successful school experience. This presentation will address the needs of the student as well as his classmates. It is generally intended for elementary school students and utilizes age and developmentally appropriate language, as well as materials to promote understanding of the child's illness. In certain instances, a classroom presentation is appropriate in the middle and high school settings, where there is a core group of classmates with whom the child spends the day. In rare instances, it may be appropriate for a particular classmate to be excused from the classroom presentation, and be addressed privately.

A successful classroom visit starts with an introduction of all presenters and their roles. It is helpful to establish the knowledge base of the classmates related to overall healthcare, blood disorders, their classmate's experience, and the reason for the presentation. This helps focus the information that the liaison will present to the class, as well as dispel any myths or misconceptions about the student. The role of the student during the classroom presentation will vary from child to child depending upon the individual's comfort level. This may range from simple observation to active participation as an "expert" regarding his illness and experience. The opportunity for the student to participate at his desired level serves to empower the child.

Following is a list of individuals who may be included at the classroom visit.

School Intervention Team Members at Classroom Visit

1. Hospital staff
 - Education liaison
 - Hospital-based instructor
 - Child life specialist
 - Social worker
 - Psychologist
 - Nurse/nurse practitioner
2. Family
 - Patient, as desired
 - Parent
3. School staff
 - Teacher(s)
 - Principal/administrators
 - School nurse
 - Counselor
 - School social worker

Following is a list of suggested topics to be addressed and teaching tools that are helpful in facilitating the classroom visit.

Classroom Visit

1. Medical topics

- Diagnosis
 - Not contagious
 - Not their fault
 - Incidence
 - Often chronic/life-long
 - Episodic vs. persistent manifestations
 - Frequency of hospitalizations
- Treatment
 - Types of treatment
 - Medications and routes of administration
 - Duration and frequency
- Side effects of treatment
 - Visible vs. not visible
 - Short term and long term/late side effects

2. Psychosocial topics

- Promote peer acceptance
- Teach the importance of “normal” treatment
- Suggest strategies for interventions by peers
- Encourage teamwork
- Offer character building lessons
- Provide emotional support

3. Teaching tools

- Medical teaching dolls/puppets
- Books
- Videos
- Individualized PowerPoint® presentations
- Photographs and drawings
- Innovative, homemade supplies (such as “blood soup”, clay models) made with readily available and inexpensive material

The following is a checklist that may be helpful prior to a classroom visit. It includes much, but not all, of the specific content that is commonly addressed at a classroom visit.

Classroom Visit Topics

- ☐ Describe options for patient involvement, if desired (e.g., showing port, leading discussion, changing slides, answering questions, and handing out materials)
- ☐ Prepare patient to answer questions of other students
- ☐ Explain basic anatomy and biology: normal and disease Use age appropriate medical terminology
- ☐ Give realistic and honest information, yet avoid "doom & gloom"
- ☐ Dispel myths (e.g., illness is punishment, or illness is contagious)
- ☐ Describe the hospital experience
- ☐ Promote empathy. "How do you feel when you are sick?"
- ☐ Use teaching tools (e.g., books, videos, puppets, photos)
- ☐ Explain ports, catheters, shunts
- ☐ Describe wheelchairs or crutches
- ☐ Clarify permission for frequent drinks and snacks
- ☐ Clarify permission for frequent breaks/bathroom visits
- ☐ Explain changes in appearance (e.g. hair loss, weight gain/loss, or puffiness from steroids)
- ☐ Describe temporary and long-term changes in physical ability (e.g., fatigue, motor skills, hearing, and vision)
- ☐ Discuss social stigma
- ☐ Encourage connectedness to peers/avoid isolation
- ☐ Discuss importance of "how to be a friend"
- ☐ Share examples of what friends can do (e.g., cards, calls, text messages, e-mail, and instant messages)
- ☐ Discourage treating patient differently
- ☐ Recommend the buddy system
- ☐ Discourage teasing
- ☐ Educate students about illness prevention
- ☐ Recognize patient's courage and hard work (e.g., bravery badge, hero coloring sheet, or verbal praise)
- ☐ Discuss teamwork toward a smooth transition
- ☐ Address possibility of death, as appropriate

Chapter 7

Time . . .

Support During Palliative and Bereavement Care

The liaison plays an important role in assisting families and school personnel throughout the entire course of a child's illness. One of the most difficult and challenging times for the liaison is when the child's medical condition worsens. Despite progression of disease and likelihood of death, the child often yearns to remain connected to school and classmates. The liaison helps facilitate the child's request to participate in school as circumstances permit. This chapter will explore important topics to address during faculty and classroom visits to support the students, staff and family during this very difficult period.

For the dying child the purpose of attending school often changes. Long-term goals are redirected to daily achievements and accomplishments. Once consent is obtained from the family, the liaison collaborates with the family, student and educators to identify priorities and realistic expectations. Family members are invited to attend the faculty meeting. The primary goal of the faculty meeting is to facilitate a clear understanding of the dying child's educational, emotional and physical needs as the child transitions from attendance at school to end of life care in the home, hospital or hospice.

Discussions with school personnel at this time should include the principal or assistant principal, school nurse, guidance counselor, school social worker, school psychologist, and all related classroom teachers and other personnel with whom the child has come into contact. The liaison will act as a "point of contact" for facilitating connections and communication between all school personnel and related services.

The meeting should begin with an introduction and explanation of the roles of all members present. The liaison and any other members of the medical team explain that they are specialists from the child's hospital who are on hand to disseminate the necessary information that can assist the child in attending school and make the child's transition from school to home or hospice palliative care as smooth as possible. Information discussed with school personnel allows for a greater appreciation of the needs of the dying child and family. The liaison works closely with the faculty in hopes of creating a plan to make each day the best it can be. The liaison discusses the educational expectations with the faculty. While educational goals may be limited, it is important that the dying child continues to feel a sense of purpose. In addition, giving the child an opportunity to create something in the classroom or at home or in hospital helps to leave a legacy to his peers, school and family. Teachers will thus need to identify the dying child's goals in the class (e.g. "What would you like to do today?"). At the close of the faculty meeting, all members of the school staff that are involved with the dying child should have had time for questions to be answered and concerns to be addressed. The liaison exchanges telephone numbers and email addresses so that continued support and guidance can be facilitated.

The child may develop unique relationships among ancillary staff. These include lunch aides and lunchroom staff, special teachers (art, physical education, and computer), the "greeter" at the front desk of the school, custodial staff, librarians, and related service providers such as tutors or home-based instruction teachers. Ancillary faculty members are often less informed about an ill student's medical prognosis, and yet they are just as likely to have creative and honest connections to the child. In recognition of these relationships, when a student is dying, a separate ancillary faculty meeting should be considered to provide medical information and emotional support.

School personnel working with a dying child may be left struggling with questions about the safety and physical and emotional security of their own loved ones, the reasons for sickness in the world, and the need for protection against the pain of human suffering. Teachers, school nurses and related faculty who interact with the dying child may be left with "post-traumatic stress" symptoms. School faculty may thus find themselves vulnerable to lowered frustration tolerance, lowered tolerance for the workload of the school day, a diminished sense of safety, and a predisposition to see the world negatively. It may be helpful for the liaison to remind teachers and faculty to reach out to friends, clergy, colleagues, or therapists. These alliances are important because they allow school personnel to be cared for, and provide them with validation and support.

The following is a list of suggested topics to be discussed at the faculty meeting for the dying child.

Content Discussed at Faculty Meeting for the Dying Child

1. Medical topics
 - Diagnosis
 - Current condition
 - Palliative treatment
 - Symptom/pain management
 - Daily medications
 - Physical limitations
 - Physical appearance
 - Accommodations
 - Resuscitative measures (Do Not Resuscitate Order)
2. Psychosocial topics
 - Emotional impact (e.g., fear, anxiety, anger, sadness, depression, and withdrawal)
 - Dying child's mental status/level of awareness/gravity of situation
 - Psychological strengths
 - Coping strategies
 - Support systems/peer support
 - Supportive measures (e.g., cards, letters, class pictures, classroom newspaper, and special visits if possible, etc.)
3. Educational topics
 - Educational expectations
 - Accommodations, 504, IEP's

Children with progressive cancer have increasing frequency of school absences due to medical treatments, their side effects, and advancing disease. Repeated hospitalizations, outpatient doctor visits, and general malaise and fatigue all interfere with the child's ability to maintain proper and consistent attendance in school. In the circumstance of a life-limiting diagnosis, or when the child has entered into a palliative care and end-of-life phase of cancer, questions and concerns from classmates eventually arise. Fears about their friend's medical condition, his or her abilities and disabilities develop. A visit to the child's classroom can be provided by the liaison. This is a helpful step in assisting classmates and faculty alike to successfully navigate this medical and emotional journey.

Following is an outline of suggested topics to be addressed during the classroom visit.

Content Discussed at Classroom Visit for the Dying Child

1. Medical topics
 - Diagnosis
 - Not contagious
 - Not the child's fault
 - Rare/Incidence
 - Health promotion and wellness
 - Treatment
 - Types of treatment
 - Medications and routes of administration
 - Duration and frequency
 - Cancer may be stronger than the medicines that we have

- Side effects of treatment/illness
 - Visible vs. not visible
 - Physical appearance/changes
 - Frequent absences
 - Fatigue/limited physical activity
- 2. Psychosocial topics
 - Acceptance
 - Empathy, compassion, respect
 - Encourage communication
 - Treat normally
 - What friends can do to help
 - Ways to decrease isolation
- 3. Teaching tools
 - Medical teaching dolls/puppets
 - Books
 - Videos
 - Individualized Powerpoint® presentations
 - Photographs and drawings
 - Innovative, teaching supplies/techniques that help relate to the child

Answering Difficult Questions in the Classroom

The question "Is my friend going to die?" is often asked and, in the case of the child who is receiving palliative care at the end of life, the answer needs to be given very carefully. Research on children and trauma implicates several individual characteristics that influence a child's response to stressful situations. These are: the child's constitutional temperament, his level of cognitive and emotional development, the types of relationships the child has with his caretakers and social network, and the presence of previous stressors and losses in the child's family.

Regardless of age and temperament, however, all children need to be offered information about the dying process of a fellow classmate first as a hypothetical case. Statements that are definitive at this stage are hard for children to integrate and will likely be resisted.

One technique that is useful is to pose the question of their classmate's possibility of death back to them. "What do you think will happen to your friend?" Allow time for open discussion and exploration of the classmate's thoughts and fears.

"Your friend may die," is another way to introduce the idea that their classmate has entered into a terminal phase of his cancer. This type of speech allows the child to prepare in steps for the "dawning awareness" of the reality of death. In addition, for many children, religion and spirituality play a strong role in their willingness to accept this news. Some children may believe that God or another deity may intervene; it is prudent as well as ethical not to disabuse any child of his personal or religious belief.

Addressing the Educational Needs of Siblings, Relatives, and Special Friends

The educational issues for the child whose sibling, relative, best friend, boy- or girlfriend is dying are manifold, ranging from obvious signs of fear and sadness or mild disorganization due to disruptions in school attendance and family cohesiveness, all the way to severe emotional distress. Other signs to look for include distress, withdrawal, aggression, shock, and compromised school performance.

Teachers of siblings and special friends thus need to be made aware of the strength of their special ties with the dying child, as it may give rise to changes in their classroom performance.

Some specific signs of distress to look for include:

- Increased anxiety or persistent fears, at times accompanied by a heightened startle response
- Regressive tantrums, more often in younger children
- Withdrawal from social interactions with peers
- Increased distractibility/limited attention span/forgetfulness
- Decline in school performance

Whether the above symptoms or behaviors are a function of learning issues specific to the child or are related to emotional disruptions brought about by the trauma of chronic illness in the home or friendship, greater appreciation of the sibling's or special friend's personal and family struggles is needed before appropriate action can be taken. More specifically, children who come from homes with terminal illness may have difficulty adequately controlling their distractibility at this time. Some basic accommodations will be helpful in order to allow siblings and special friends to continue to learn and feel successful as they cope with their feelings of sadness and anxiety. Modifying the child's education plan away from the concrete academic demands of the day while still maintaining a vigilant eye on school requirements and appropriate learning will help these children to feel good about themselves and their academic performances.

The following are possible educational accommodations and recommendations that may be provided to siblings and special friends as they anticipate the loss in their lives. Though the provisions of flexible timing and modified assignments should be offered, the structure and academic plan of each school day should remain consistent and stable.

Accommodations for Siblings or Special Friends

1. At school
 - Employ preferential seating (front of room, close to teacher) to cue the student to maintain focus
 - Offer reduced workload without compromising content
 - Provide an extra set of books and handouts as forgetting can be an issue
 - Facilitate the possible need for privacy and space when sadness or pain suddenly arises
 - Provide a subtle cue, such as the raising of a pen, as a surreptitious means to help the sibling or special friend prevail during the workday
2. At home
 - Use a homework checklist with small rewards for completing each subject
 - Provide a consistent, distraction-free work space in close proximity to supervision
 - Schedule frequent breaks with opportunities for physical activity

Recommendations for Siblings or Special Friends

- Offer psychosocial screening/assessment
- Consider referral for support by school psychologist, school nurse, social worker and/or guidance counselor
- Provide information on support groups, special programs and camps
- Identify a support teacher or school faculty person for student to reach out to during school
- Provide a system for the student to dismiss him/herself from the classroom and meet with the support teacher/faculty person should the urgent need arise

When a Child Has Died

Following the death of a child, the liaison provides a faculty meeting to disseminate the necessary information that will guide all members of the school community through this next difficult step of bereavement. The meeting should begin with a re-introduction and description of the roles of all members present. The goal at this time is to optimize the emotional wellbeing of the school faculty and classmates who are impacted by the loss.

During the faculty meeting the primary objective is to help facilitate an honest understanding of the events that have occurred around the student's death (permission from the bereaved family should be obtained prior to the faculty meeting). The liaison explores ways to share this information with classmates and other members of the child's school community, in a language that is developmentally appropriate and psychologically sensitive. Another important objective is to offer support and guidance to school personnel who may also be experiencing sadness and pain over the loss of their student. Discussions with faculty members at this time should include the principal or assistant principal, school nurse, guidance counselor, school social worker and/or school psychologist, and any and all related classroom teachers and other personnel with whom the child had contact. The same liaison that was present at the first meeting should return for this next important meeting. The process of integrating emotionally charged information might be facilitated more effectively when the school faculty has an existing and trusting relationship with representatives from the child's medical team.

In recognition of the unique and special relationships that ancillary faculty often establish with a dying child, a separate meeting is recommended. Ancillary faculty members are often less informed about the details of a student's death; they may not work full-time in the school building and/or they may have seen the student less often than did classroom teachers. Nevertheless, this part of the faculty will be in need of similar guidance and support.

Content Discussed at Faculty Meeting

1. Medical information

- Events leading up to death
- Overview of diagnosis and treatment
- Gentle description of the death

An important outcome from this discussion should be a clearer understanding of the medical reasons for the death, so that rumors and erroneous information (which can often be more upsetting than the actual reason for death) are not circulated among the faculty and larger school community.

2. Psychosocial information

- Emotional impact
- Peer relations
- Discussion of child's and family's wishes

School bereavement is a complex psychosocial process whose complexity stems deeply from the reality that the death of a student re-stimulates earlier, more personal losses in each survivor's life. Therefore, faculty members may need to express a wide range of emotions regarding the loss they are learning about during this meeting. Time should be allotted for open discussions about the staff members' feelings at this time, as their own level of acceptance of the child's death will impact their ability to help the students in their school.

3. Telling the students
 - Dependent on students' ages and cognitive development
 - Include the school guidance counselor, social worker and/or school psychologist in this discussion as these professionals will often be directly involved in providing support to grieving students in the school
4. Anticipating students' reactions
 - A child's initial response to the news that a friend or classmate has died may involve "resistance"
 - School personnel must be made aware that childhood grief is not a linear process or one that occurs in predictable stages; a child may express understanding one day and disbelief the very next, only to be followed by anger or other related themes
 - The liaison can help school personnel anticipate the various ways that grief may manifest among the child's classmates; children grieve differently than adolescents and adults
 - Monitor difficulties in school performance; altered sleep and appetite, irritability and poor social relations may become the open expressions of a child's emotions
 - Educators should be on the look-out for changes in individual and group dynamics in their classroom or school environment as a whole
5. Establishing a "Quiet Room"
 - "Quiet Rooms" or "Drop-In Clinics" can be a helpful part of the crisis intervention and healing process right after a student has died
 - The school's social workers, psychologists, nurse and guidance counselors may decide where the drop-in clinics will be situated (preferably in areas that are quiet and out of the way of being seen)
 - These quiet rooms should be staffed by at least one trained professional per room
 - Names and addresses of qualified grief counselors should be furnished by the liaison, if available
6. Creating a memorial
 - A ritual event or building a "monument" to honor the student who died is another valuable step in the healing process for the school
 - Children who are grieving need a place and a process through which they can express their feelings; they also need to be given permission to "move on"
 - Helping the school personnel to create a planned event for the class or the entire school can effectively punctuate the end of this time in the student's school experience
 - The planting of a tree or the dedication of a playground in the student's name, for example, should thus begin to be organized
 - Students can be offered opportunities to help with this process, either through fund raising efforts or consciousness raising discussions amongst their peers
 - In this way the school faculty allow students to mobilize through their grief and to discover ways to feel helpful and effective in the sad days and weeks ahead

Once the faculty and ancillary staff meetings have been held, a visit to the child's classroom may be offered by the liaison. This can be an important step in helping classmates and teachers navigate this emotional journey as a class and as a school community. The visit starts with a brief but sensitive explanation of what happened to their friend and classmate. Depending upon age and the class members' developmental understanding of the death concept, the children are told that their friend has died. The use of metaphor in place of the actual word "died" is not recommended, as many children think magically, especially at younger ages, and they therefore may misinterpret the meaning of this important discussion. They are told that his or her body has "stopped working". For younger children, it is helpful to speak in concrete terms such as: "He no longer burps, hiccups or coughs and his body no longer needs the medicine that it was given." Older children may appreciate more abstract statements such as: "The medicine that was used to fight the sickness was not as strong as the cancer itself."

Regardless of the age, children need information that is clear and comprehensible. Their ability to understand the information that is given to them will depend on their ability to deal conceptually with abstractions, namely that death is universal, causal and irreversible. Their understanding will also be affected by previous experiences with the deaths of other people and pets in their lives. (See Appendix D for more detailed information.)

Content Discussed at Classroom Visit

1. Medical information about the child's death
 - Science/biology of disease
 - Events leading up to death
 - Overview of diagnosis and treatment
 - Gentle description of the death
2. Psychosocial information
 - Emotional impact
 - Emotional support
 - Peer relations
 - Dispel myths
 - Wake and funeral services
 - Additional resources (school and community)

Classmates and friends can be encouraged to write stories about their friend if a home visit is unavailable. Finding ways to memorialize their classmate through the sharing of stories, artwork, music or pictures can help classmates feel involved in the care of their friend's memory. The use of computer blogs and personal websites such as "Facebook" or "CaringBridge" can be helpful ways to memorialize a classmate with more far-reaching effects.

Resources to Empower and Support School Faculty

1. *When Death Impacts Your School: A Guide for School Administrators and Helping the Grieving Student: A Guide for Teachers*
These are excellent resources that explain the process of how death impacts students and ways that school personnel can help. They are available through the Dougy Center, an organization providing support to grieving children and families (<http://www.dougy.org>)
2. Compassionate Friends is an organization that offers suggestions for teachers and school counselors to manage grief in the classroom. The organization's website is www.compassionatefriends.org
3. Hotline and other telephone numbers where further support can be attained locally

While bereaved children show a variety of negative behaviors, many of them are short-lived and remit on their own. The focus should thus not be on the presence of a symptom or a behavior, but on the *duration* of a symptom.

Following is a checklist of behaviors that should be addressed by a professional if they *persist for several months*.

Behaviors to be Addressed by a Professional

- ☐ If a child has a persistent style of talking about the classmate who died, it may be a sign for further investigation
- ☐ If clinginess or enduring anxiety exists in the child during classroom activities, then the child should be evaluated
- ☐ The presence of somatic complaints is not uncommon after a death has occurred. As mentioned earlier, children express grief in different ways, and aches and pains may be one sign of their sadness. If somatic complaints persist, and frequent visits to the nurse or guidance counselor ensue, medical and psychological attention may be required
- ☐ Persistent nightmares and sleeping difficulties could be a sign that professional attention is needed
- ☐ Prolonged changes in eating habits, weight loss and/or refusal to eat lunch, or weight gain, may be detected by lunchroom aides and should be brought to a professional for greater attention
- ☐ Marked social withdrawal at a time when other classmates are re-engaging with one another also may require attention
- ☐ Prolonged and serious academic reversal and poor scholastic performance may also be an indication that greater help is required
- ☐ Signs of self-destructive behavior or suicidal ideation and/or suicidal statements should always be referred regardless of the time and duration. While this behavior is less common, it should always be taken seriously. Some children miss their friend so much they wish to die in an attempt to be re-united with him. Other, older, students who have a history of suicide in their own family may experience the death of a classmate on a more personal level; recapitulating for them memories of a suicide that left them bereft and confused

It is difficult for a school faculty to assess the difference between normal bereavement and clinical depression. Thus, maintaining close contact with the liaison can ensure all school personnel that their children and faculty alike will be cared for in the most appropriate and efficient manner during this very difficult time.

Chapter 8

Back of the Pack: Supporting Siblings in School

A diagnosis of cancer, blood disorder or other chronic illness affects the entire family. Siblings experience many different feelings, which often go unnoticed or unaddressed, as the family's focus turns to the newly diagnosed child. Supporting the sibling(s) both at home and in school is often overlooked, due to the increased stress placed on the family. Daily routines are interrupted while parents are dealing with and sorting through this new reality. When a child in a family is diagnosed with a life-threatening illness, the well siblings may also suffer.

Researchers have suggested that siblings living with this changed family dynamic often experience feelings of fear, anxiety, sadness and isolation, among others (Woodgate, 2015). Love and concern for the ill sibling can instigate emotional conflict, as other feelings such as abandonment, jealousy and resentment are also a reality. The wide fluctuation in feelings can put well siblings at greater risk for difficulties emotionally, socially, and academically. Teachers, as well as other school personnel, should be aware of behavioral changes that may be exhibited by the sibling of a child with cancer or blood disorder. School staff may observe declines in academic performance or struggles with interpersonal relationships. Not all changes are negative; positive behavioral changes can also be a warning sign. Siblings may be observed to expend more effort to please others or may take on more responsibility than is appropriate in an effort to feel valuable or important. The siblings may minimize their own feelings as a protective mechanism to manage all the many emotions they are experiencing at home (Ingram, 2011). It is important to not assume the sibling of a child diagnosed with cancer or chronic illness is without concern just because they appear to be coping with the stress and say they are fine.

The following lists include symptoms that may be observed in school and should receive attention as well as some potential interventions.

Key Symptoms School Personnel Should Monitor

1. Social withdrawal
2. Crying
3. Low frustration tolerance
4. Rebellious
5. Poor academic performance
6. Inattentive behavior
7. Disruptive behavior

Ways School Personnel Can Help

1. Maintain normal classroom routines
2. Provide academic support and or counseling
3. Communicate concerns with parents
4. Ask parents for updates on sick child
5. Ask permission to share information with other students/parent (See *Classroom Visit* Section below)
6. Provide peer support
7. Acknowledge Feelings
 - Recognize emotions related to loss of parental attention
 - Validate experiences

As the educational specialist/liaison obtains consent to contact the school of the ill child, it is important to inquire about any school-aged siblings and their level of academic functioning prior to their sibling's diagnosis. This is an important step as siblings' grades and behavior can often change when their life is altered by the family trauma. As in Chapter 2, the educational specialist/liaison can play an important role in facilitating communication with the school. The liaison acts as the bridge to inform and update school personnel about the ill child's medical status. The liaison can also facilitate faculty meetings and classroom visits to address the educational and emotional needs of the brother(s)/sister(s).

Following is a list of information that should be gathered about school-aged siblings.

1. Sibling School Information
 - Age and grade
 - School name
 - Identification of school personnel for communication
2. Questions to ask
 - Does the sibling have a 504 or Individualized Education Plan (IEP)?
 - How was the siblings' behavior prior to diagnosis?
 - Has there been a change in behavior or academic functioning since siblings' diagnosis?
 - What support systems are available (friends, family, teachers, etc.)?

After the initial assessment and gathering of sibling information, the liaison, family, and school should consider the following services.

Services of the Educational Liaison

1. Contact school personnel to discuss siblings' diagnosis/treatment
2. Provide school with "communicable" disease letter (see Appendix K)
3. Invite the classroom teacher to faculty meeting if siblings attend same school
4. Include sibling and/or siblings classmates in classroom presentation
5. Identify a contact person within the school, to maintain open communication
6. Arrange a contact or "go to" person within the school for the sibling
7. Facilitate any needed interventions (504/IEP accommodations, behavior plan, counseling, tutoring, etc.)

The following is a list of individuals who may be included at the faculty meeting.

School Intervention Team Members at Faculty Meeting

1. Hospital staff

- Educational specialist/liaison
- Hospital-based instructor
- Child life specialist
- Nurse/nurse practitioner
- Physician
- Psychologist*
- Social worker*

*These professionals have expertise in addressing psycho-social issues and aspects of illness and disability. They can be extremely helpful to the child, family, classroom teacher, school personnel, as well as the liaison. They may provide input for the development of a 504 Plan or IEP if needed. If unable to physically attend the faculty meeting, and when appropriate, they should be available via conference call to discuss resources/services that are available to the sibling within the community.

2. Family

- Parents/guardians
- Child, depending upon age and request
- Other family support (i.e. translator, advocate, or clergy)

3. School staff

- Teacher(s) from sibling classroom
- Principal/administrator
- School psychologist
- School social worker
- Guidance counselor
- School nurse
- Additional professionals if sibling has 504 Plan/IEP
 - Para-professionals (aides, monitors, etc.)
 - Special Education/504 coordinator
 - Physical therapist
 - Occupational therapist
 - Speech therapist

The following is a list of suggested topics to be addressed during the faculty meeting.

Content Discussed at Faculty Meeting

1. Psychosocial topics

- Emotional impact and psychological adjustment to siblings' illness
- Peer relations
- Child's understanding of illness
- Developmental issues
- Family and sibling issues and support
- Social skills training
- Social phobia

2. Educational topics

- Acute educational issues
- Attendance policies related to lateness, excused vs. unexcused absences, flexibility with attendance policy for siblings
- Tutoring to bring student up to grade level
- School phobia
- Truancy

The educational specialist/liaison works closely with the hospital and school social workers to identify community resources and provide referrals to supportive services for the family, including the sibling. It is important for the sibling and family to maintain a routine as close to typical as possible.

The following checklist may be helpful to review prior to a faculty meeting. This list includes much, but not all, of the specific content that is commonly addressed at a school faculty meeting. By reviewing this checklist with the child's treatment team prior to the faculty meeting the educational liaison can determine which topics are relevant and how they may be addressed at school for each individual child.

Psychosocial Topics

- ☐ Dispelling myths about illness
- ☐ Impact of illness and treatment on family dynamics
- ☐ Fear
- ☐ Anxiety
- ☐ Social stigma
- ☐ Effects of isolation
- ☐ Value of normalcy
- ☐ Value of school
- ☐ Connectedness to peers via school
- ☐ Suggested coping strategies
- ☐ Discuss need to educate peers and encourage peer support group

Educational Topics

- ☐ Anticipate intermittent attendance due to doctors' appointments with sibling or hospitalizations (excused vs. unexcused absences)
- ☐ Address academic worries
- ☐ Review student's academic performance level prior to siblings' illness
- ☐ Evaluate and provide supportive services (e.g., occupational therapy, physical therapy, speech therapy)

After the faculty meeting, it is important to suggest including the sibling and his classmates in the patients' classroom visit. For additional information on classroom visits please see Chapter 4.

The following is a list of individuals who may be included at the classroom visit.

School Intervention Team Members

1. Hospital staff
 - Educational specialist/liaison
 - Child Life Specialist
 - Nurse/nurse practitioner
2. Family
 - Patient, as desired
 - Sibling, as desired
 - Parents, as desired
3. School staff
 - Teacher(s)
 - Principal/administrators
 - School nurse
 - Counselor

The following is a list of suggested topics to be addressed and teaching tools that are helpful in facilitating the classroom visit. If the patient/student and/or their classmates are not participating in the classroom presentation, the presentation for the sibling's classmates can be referred to as a Health and Wellness Presentation.

Classroom Visit

1. Medical topics
 - Diagnosis
 - Not contagious
 - Not the child's fault
 - Rare/Incidence
 - Pediatric vs. adult illnesses
 - Treatment
 - Types of treatment
 - Medications and routes of administration
 - Duration and frequency
 - Side effects of treatment
2. Psychosocial topics
 - Promote peer acceptance
 - Encourage normalcy in peer relations
 - Suggest strategies for interventions by peers
 - Encourage teamwork
 - Offer character building lessons
 - Provide emotional support (such as: lunch bunch/buddy or other opportunities for peers and siblings within the school setting)
3. Teaching tools
 - Medical teaching dolls/puppets
 - Books (see Appendix L)
 - Videos
 - Individualized PowerPoint® presentations
 - Photographs and drawings
 - Innovative, homemade supplies (such as: "blood soup", clay models) made with readily available and inexpensive materials

The following checklist may be helpful prior to a classroom visit. It includes much, but not all, of the specific content that is commonly addressed during a classroom visit.

Classroom Visit Topics

- ☐ Describe options for child's involvement, if desired (leading discussion, answering questions, and handing out materials)
- ☐ Prepare patient/sibling to answer questions from other students
- ☐ Explain basic anatomy and biology—normal and disease
- ☐ Use age appropriate medical terminology
- ☐ Give realistic and honest information, yet avoid "doom & gloom"
- ☐ Dispel myths (e.g., illness is punishment, cancer is contagious)
- ☐ Describe hospital experience
- ☐ Promote empathy. "How do you feel when you are sick?"
- ☐ Use teaching tools (e.g., books, videos, puppets, and photos)
- ☐ Explain ports, catheters, and shunts
- ☐ Describe wheelchairs or crutches
- ☐ Clarify permission for frequent drinks and snacks
- ☐ Clarify permission for frequent breaks/bathroom visits
- ☐ Explain changes in appearance (e.g., hair loss, weight gain/loss, puffiness from steroids)
- ☐ Describe temporary and long-term changes in physical ability (e.g., fatigue, motor skills, hearing, and vision)
- ☐ Discuss social stigma
- ☐ Encourage connectedness to peers; avoid isolation
- ☐ Discuss importance of "how to be a friend"
- ☐ Share examples of what friends can do: cards, calls, text messages, e-mail, and instant messages
- ☐ Discourage treating patient/sibling differently
- ☐ Discourage teasing
- ☐ Recommend buddy system
- ☐ Educate students about illness prevention
- ☐ Address possibility of death, as appropriate
- ☐ Recognize patient/sibling's courage and hard work (e.g., bravery badge, hero coloring sheet, and verbal praise)
- ☐ Discuss teamwork toward a smooth transition

References:

- Ingman, K.A. (2011). Helping Siblings in the Classroom. In *Educating the Child with Cancer: A Guide for Parents and Teachers*. N.p.: ACCO, 2011. 271-77.
- Woodgate, R.L. (2015). Siblings' Experience with Childhood Cancer: A Different Way of Being In the Family. *Cancer Nursing*. Web.

APPENDIX A

Sample Consent to Contact School

CONSENT FOR RELEASE OF MEDICAL INFORMATION	
Date: _____ Medical Record Number: _____	
Patient: _____ Date of Birth: _____	
(Last name) (First name) (Middle initial)	
(Home Address)	Telephone Number: _____
Authorization is hereby granted to University Hospital to provide _____ <div style="text-align: center; font-size: small;">(Name and Address of third party or names of any duly authorized representatives)</div>	
with access to my medical/hospital records for the purpose of review and requests you provide such copies thereof that may be requested.	
Release of such information is limited as indicated below: (please check one)	
<input type="checkbox"/> 1. Confined to records regarding admission and/or treatment for the following medical condition or injury: _____	
<input type="checkbox"/> 2. Covering records for the period from _____ to _____ <div style="text-align: center; font-size: small;">Date Date</div>	
<input type="checkbox"/> 3. Confined to the following specified information: _____	
<input type="checkbox"/> 4. No limitations placed on dates, history of illness, or diagnostic and therapeutic information, including any treatment for alcohol and drug abuse. <div style="text-align: center; font-size: small;">(Signer must initial for authorization of this response) _____</div>	
Expiration date of this authorization, if any: _____	
Date: _____ Signature of Patient: _____	
If consenting party is other than the patient:	
_____ Signature of Other	_____ State Relationship
Any disclosure of medical record information by the recipient(s) is prohibited except when implicit in the purposes of this disclosure.	

APPENDIX B

Sample Intake Form

Hematology/Oncology Patient Summary

MR#: _____

Patient Name: _____

DOB: _____

Diagnosis: _____

Date of Diagnosis: _____

(Relapse date: _____)

Treatment: ☐ Chemo/ IT IV oral ☐ Radiation ☐ Surgery ☐ BMT

MD: _____ PNP: _____ SWK: _____ Psych: _____

Parent Name: _____

Address: _____

Home Phone: _____ Other Phone: _____

School/District: _____ Grade @ Dx: _____

Address: _____

Contact person: _____

Phone #: _____ Fax #: _____

Developmental/Academic History:

Preschool attendance: ☐yes ☐no Kindergarten entry date: _____

IEP in place: ☐yes ☐no Date:_____ Designation: _____

504 Plan in place: ☐yes ☐no Date:_____

Neuropsych referral: ☐yes ☐no Date:_____ Feedback: _____

Repeated grade: ☐yes ☐no (grade repeated _____)

Academic performance prior to diagnosis (GPA): _____

OGT status: Read—pass/fail Writing—pass/fail Math—pass/fail
Citizenship—pass/fail Science—pass/fail

Academic performance at LTFU entry: _____

Transition reviewed: ☐yes ☐no Date: _____ High School Grad date: _____

Post-Secondary Plans: _____

Academic Services/Plan:

Home Instruct Request sent: ☐yes ☐no Date: _____

Hospital teacher assigned: ☐yes ☐no Date:_____

Packet #1 to school: ☐yes ☐no Date: _____

Classroom visit: ☐yes ☐no Date: _____

Anticipated Re-entry: Date: _____

Packet #2 to School: ☐yes ☐no Date: _____

Actual Re-entry: Date: _____

Classroom visit at Re-entry: ☐yes ☐no Date: _____

APPENDIX C

Books for Children, Parents and Teachers

Books for the Classroom When a Student has Cancer

Bridge, C. (2001). *Andrew's Story: A Book About a Boy Who Beat Cancer*. Lexington: Lerner Publishing Group.
An account of survival of childhood cancer told in the voice of a 9 year old.

Cain, B. (2001). *Double Dip Feelings: A Story to Help Children Understand Emotions*. Washington DC: Magination Press.

This book discusses how it is natural to feel contradictory emotions.

Cole, J. (1989). *The Magic School Bus: Inside the Human Body*. New York: Scholastic, Inc.
Ms. Frizzle and the students learn about how the body works.

Foss, K. (1996). *The Problem with Hair: A Story for Children Learning About Cancer*. Omaha, NE: Centering Corporation.

This poem is about friends, including one who loses hair to chemotherapy.

Giugliano Trezza, D. (2002). *James Bounces Back...Back to School*.

Self-published; contact the author to purchase.

A story about a boy who returns to school following a cancer diagnosis.

Giugliano Trezza, D. (2002). *Jessie Bounces Back...Back to School*.

Self-published; contact the author to purchase.

A story about a girl who returns to school following a cancer diagnosis.

Henry, C.S. & Gosselin, K. (2001). *Taking Cancer to School*. Plainview, NY: JayJo Books.

Story of school aged boy going through cancer treatment.

Krishner, T. (1992). *Kathy's Hats*. Morton Grove, IL: Albert Whitman & Co.

A story about a girl whose love for hats comes in handy when she loses her hair from chemotherapy.

Martin, K. (2005). *H is for Hair Fairy*. Victoria, BC, Canada: Trafford Publishing.

An alphabet book about cancer.

Negron, R. (2006). *The Boy of Steel*. New York: HarperCollins.

The story of a boy who learns about courage and strength with the New York Yankees.

Polacco, P. (2007). *The Lemonade Club*. New York: Philomel Books.

The story of a fifth grade girl who struggles with leukemia but has the support of her whole class.

Saltzman, D. (1995). *The Jester Has Lost His Jingle*. Palos Verdes Estates, CA: The Jester Co., Inc.

A story about a jester who loses his laughter and sets off to find it again.

Shultz, C. (1990). *Why, Charlie Brown, Why?* New York: Topper Books.
The story of a classmate who is diagnosed with leukemia and how her friends support her.

Snyder, H. (1998). *Elvin the Elephant Who Forgets*. Wolfeboro, NH: L&A Publishing/Training, Inc.
A story about an elephant that can help children learn about brain injury and its effects on home and school.

Books for Parents and Teachers

Each of the books listed here include extensive bibliographies and resource lists.

Fried, N. (2007). *The Angel Letters: Lessons that Dying Can Teach Us About Living*. Chicago, IL: Ivan R. Dee.

Hoffman, R. I. (Ed). (2012). *Educating The Child With Cancer, A Guide for Parents and Teachers, 2nd ed.* Kensington MD, USA: American Childhood Cancer Organization (acco.org).
A resource for parents and educators of children with cancer and those who have survived it. Containing contributions from nearly forty professionals and parents, this book encourages open communication and a development of understanding between parents, teachers and the child's medical team, to enable the provision of an integrated approach to education. Subjects covered include: school and the Child with Cancer, communication, cognitive late effects of treatment, the law and the child's rights, and supporting siblings. The authors recognize that a solid education promotes confidence and lays the foundation stones of a "productive and rewarding life".

Janes-Hodder, H. & Keene, N. (2002). *Childhood Cancer: A Parent's Guide To Solid Tumor Cancers, 2nd ed.* Sebastopol, CA: O'Reilly & Associates, Inc.

Keene, N. (2002). *Childhood Leukemia: A Guide For Families, Friends, & Caregivers, 3^d ed.* Sebastopol, CA: O'Reilly & Associates, Inc.

Shiminski-Maher, T., Cullen, P. & Sansalone, M. (2002). *Childhood Brain & Spinal Cord Tumors: A Guide for Families, Friends & Caregivers*. Sebastopol, CA: O'Reilly & Associates, Inc.

APPENDIX D

Questions that May Arise during a Classroom Visit for a Child Who has Died, with Suggested Responses

1. Did he feel any pain?

The answer to this question may or may not involve medical data. Depending upon the age of the classmates, it may be sufficient to state that "their friend felt no pain"; that "there was medicine used to take away any feeling of pain or discomfort at the time of his death". Metaphors such as "he went to sleep" will be frightening to young children and should not be used as they can contribute to the development of sleep difficulties.

2. How did he die?

A global response regarding the biological process of dying may be necessary here. First a teacher can say that "the disease that the child had was stronger than the medicine the doctors used to keep him alive. Eventually he stopped breathing, his heart stopped beating and he was no longer living".

3. What did they do with his body?

The processes of burial and/or cremation vary according to culture and religion, and the answer to this question needs to be consistent with the plans that the child's family have decided upon. If a burial is planned, young children might thus be told about the process of a funeral and related burial rituals so that no magical thoughts ensue. Children can be told that "the child's body was placed in a box that is called a coffin. The coffin was (or will be) placed into a hole in the ground. The hole was (or will be) covered with soil and a marker or stone will be placed there so everyone will know where his body remains." If the plan is cremation, clear and elementary language must be used to explain that this is a process of changing the body quickly. Clear language is essential so that all children understand the explanation given to them. Depending upon the spiritual appreciation of the children in the classroom, a discussion of "soul" or "spirit" may arise. The children themselves may discuss metaphors such as: their friend's soul left his body like a butterfly leaves a cocoon. In addition, specific belief systems may be insinuated into the class discussion. The important message to convey to the class is that their friend's body no longer works; their friend has died and he no longer feels pain.

4. Will his mother and father (and siblings) be alright?

The death of a classmate often elicits in children anxiety that the classmate's family will not survive without the child who has died. In addition, some children fear that there will be other deaths in that same family. At this time it is important to explain that, although the members of their friend's family are very sad about his death, they will someday learn how to smile and enjoy life again. When these fears are addressed directly, and the appropriate reassurances are given, children will not need to make up stories that "fill in the gaps."

5. Could I have done anything to make this happen?

Children need to know that they did not cause the death out of their anger, bullying or negative thoughts. Children learn early that strong feelings can hurt another person, thus they need to be reassured that nothing they felt, said or did has contributed to the death. Adolescents in particular can have ambivalent or coexisting feelings of love and hate for a peer, and their last interactions with the child who died may have been marked by volatility or unmet needs. Such teenagers are very much in need of reassurance that any fights or angry exchanges that transpired in the last weeks or days of their friend's life played no part in his or her death. It is necessary to remember that certain classrooms and school communities will have differing beliefs as to the appropriateness of these conversations, and school guidelines should always be referred to at such times.

6. I understand that he is dead, but when is he coming back to school?

Young children view death as a state of separation. It is not something that brings sadness to them because they have not yet achieved an abstract appreciation that death is irreversible. Thus one might hear a child below the age of seven or eight ask about the classmate's eventual return. Gentle reminders that their friend cannot return because he has died and dead people cannot come back will be necessary from time to time.

7. Can I visit his family? What can I do for them?

Adolescents commonly ask if they can visit the family of a friend who has died. The answer is best handled with a simple "I will find out." Most often, family members are eager to speak with their child's peers. Bereaved parents gain great comfort from the stories that their child's friends can tell about their loved one. However, some families may wish to remain separate and distance themselves from the school and peers to which their child was connected. Asking the family directly, before advising the student to make contact, may be the most sensitive way to handle this question.

APPENDIX E

Cancer Resources

American Cancer Society (ACS)
1599 Clifton Road, NE
Atlanta, GA 30329-4251
Phone (800) 227-2345
Web: www.cancer.org

American Childhood Cancer Organization
P.O. Box 498
Kensington, MO 20895-0498
Phone (855) 858-2226
Web: www.acco.org

American Society of Clinical Oncology (ASCO)
1900 Duke Street, Suite 200
Alexandria, VA 22314
Phone (703) 299-0150
Web: www.asco.org

American Society of Pediatric Hematology/
Oncology (ASPH/O)
Phone (847) 375-4716
Web: www.aspho.org

Association of Pediatric Hematology & Oncology
Educational Specialists (APHOES)
Web: www.aphoes.org

Association of Pediatric Hematology/
Oncology Nurses
4700 W. Lake Avenue
Glenview, IL 60025-1485
Phone (847) 375-4724
Fax (847) 375-6478
Web: www.aphon.org

Bereaved Parents of the USA
(516) 233-4848
Diana Roscigno, Long Island New York Chapter Leader
markanthonymom@yahoo.com
Web: www.bereavedparentsusa.org

Bob Sweeney's Camp Comfort/H.O.P.E.
(Affiliated with Good Shepherd Hospice)
4747-20 Nesconset Highway
Port Jefferson, NY 11776
Dsweeney4@verizon.net

Brain Tumor Society
124 Watertown Street
Suite 3H
Watertown, MA 02472-2500
Phone (800) 770-8287
Web: www.tbts.org

Camp Happy Times/Valerie Fund
2101 Millburn Avenue Maplewood, NJ 07040
Millie Finkel, Director
1-800-8-Valeri

Cancer Care, Inc.
275 7th Avenue
New York, NY 10001
Phone (800) 813-4673
Web: www.cancercare.org

CancerSourceKids
40 Tall Pine Drive
Studbury, MA 01776
Web: www.cancersourcekids.com

Cancervive, Inc
11636 Chayote Street
Los Angeles, CA 90049
Phone (310) 203-9232
Web: www.cancervive.org

Chai Lifeline/Camp Simcha
151 West 30th Street
New York, New York 10001
Toni Cabat, DSW, LCSW
tcabat@chailifeline.org
Phone (212) 465-1300
Web: www.chailifeline.org

Child Champions Network
425 New York Avenue,
Suite 205 Huntington, NY 11743
Marianne Esolen, L.M.S.W. Counseling and Consulting
Services Founder/Facilitator
marianne.esolen@yahoo.com
Phone (631) 219-3400
Web: www.doallthegood.com

Childhood Brain Tumor Foundation,
The 20312 Watkins Meadow Drive
Germantown, MD 20876
Phone (877) 217-4166
Web: www.childhoodbraintumor.org

Children's Cancer Association
Web: www.joyrx.org
Kids' Cancer Pages - National Childhood Cancer
Resource Directory

Childhood Leukemia Foundation
807 Mantoloking Rd.
Brick, NJ 08723
Phone (888) 253-7109
Web: www.clf4kids.com

Child Life Council, Inc.
11820 Parklawn Drive, Suite 202
Rockville, MD 20852
Phone (301) 881-7090
Web: www.childlife.org

Children's Oncology Group (COG)
4600 East West Highway
Suite 600
Bethesda, MD 20814-3457
Phone (301) 718-0042
Web: www.childrensoncologygroup.org

Clinical Trials.gov
Web: www.clinicaltrials.gov

COPE (Connecting Our Paths Eternally)
P.O. Box 1251
Melville, NY 11747
Phone (516) 484-4993
Karen Flyer, Executive Director
karen@copefoundation.org
Web: www.copefoundation.org

Comfort Zone Camp, Inc.
110B Meadowlands Parkway - Suite 301
Secaucus, NJ 07094
Phone (201) 867-2077
Web: www.comfortzonecamp.org

Compassionate Friends of Brookhaven (Medford)
Walter and Maxine Katz, Co-leaders
Phone (631) 738-0809
walter588@aol.com
Compassionate Friends - National Office:
(877) 969-0010
Web: www.compassionatefriends.org

Cure Search
National Childhood Cancer Foundation (NCCF)
4600 East West Highway, # 600
Bethesda, MD 20814-3457
Phone (800) 458-6223
Web: www.curesearch.org

Friends of Karen, Inc.
21 Perry Street
Port Jefferson, NY 11777
Phone (631) 473-1768
Web: www.friendsofkaren.org

Good Shepherd Hospice
(Affiliated with Bob Sweeney's Camp Hope)
190 Motor Parkway
Hauppauge, NY 11788
Janie Malone, L.C.S.W., PhD
jqm9269@nyu.edu
Phone (631) 474-4040

Have a Heart Children's Cancer Society
164 Main St.
Huntington, NY 11743
info@haveaheartcharity.org
Phone (631) 470-1198
Web: www.haveaheartcharity.org

Honeysuckle Foundation for Children with Cancer
P.O. Box 1491
Melville, NY 11747
Rene Giacalone
rene@honeysucklefoundation.org
Phone (631) 885-1009 or (631) 885-1006
Web: www.honeysucklefoundation.org

Hospice Care Network
99 Sunnyside Boulevard
Woodbury, NY 11797
Donna Charielle, LMSW, Children's Bereavement
Social Worker
dcharielle@hospicecarenetwork.org
Phone (516) 224-6465

I'm Too Young For This! Cancer Foundation
40 Worth Street
Suite 801
New York, NY 10013
Phone (877) 735-4673
eFax: (877) 794-6902
Web: www.stupidcancer.com

Lance Armstrong Foundation
P.O. Box 161150
Austin, TX 78716-1150
Phone (512) 236-8820
Web: www.livestrong.org

Leukemia & Lymphoma Society
1311 Mamaroneck Ave.
White Plains, NY 10605
Phone (914) 949-5213
Web: www.lls.org

Living in Love
Pediatric Hematology/Oncology
Palliative Care & Bereavement Program
Stony Brook University Medical Center
Department of Pediatric Oncology
HSC 11-020 Stony Brook, NY 11794-8111
Rosemary Mahan
Rosemary.mahan@stonybrook.edu
Phone (631) 444-7720
Web: www.sunrisefund.org

Living Through Learning Foundation
28 West Francis Street
Iselin, NJ 08830
David S. Gordon
Phone (732) 476-7242
Web: www.livingthroughlearning.org
info@livingthroughlearning.org

Make-A-Wish Foundation of America
3550 North Central Avenue, Suite 300
Phoenix, Arizona 85012-2127
Phone (800) 722-9474
Web: www.wish.org

Morgan Center
P.O. Box 333
Brightwaters, NY 11718
Nancy Zuch
Phone (631) 206-1341
nancy@themorgancenter.org

National Bone Marrow Donor Program
Web: www.marrow.org

National Cancer Institute
Web: www.cancer.gov

National Institutes of Health (NIH)
9000 Rockville Pike
Bethesda, MD 20892
Phone (301) 491-4000
Web: www.nih.gov

Oncology Nursing Society (ONS)
125 Enterprise Drive
Pittsburgh, PA 15275-1214
Phone (866) 257-4ONS
Web: www.ons.org

Patient-Centered Guides
Web: www.patientcenters.com

Play Fit - Stay Fit!
Stony Brook University Medical Center
Department of Physical Therapy
Stony Brook, NY 11794-8201
Raymond McKenna
Raymond.mckenna@stonybrook.edu
info@platyfitstayfit.org
Phone (631) 444-6169
Web: www.playfitstayfit.org

Ronald McDonald House
267-07 76th Avenue
New Hyde Park, NY 11040
Michael Pfeiffer, Program Manager
mpfeiffer@rmhlongisland.org
Phone (516) 775-5683, ext 133
Web: www.rmhlongisland.org

Songs of Love Foundation
P.O. Box 750809
Forest Hills, NY 11375
John Beltzer, Director
john@songsoflove.org
Sara Bartley, Outreach Coordinator
sbartley@songsoflove.org
Phone 1-800-960-SONG or (718) 441-5422
Web: www.songsoflove.org

Splashes of Hope
P.O. Box 537
Huntington, NY 11743
Heather Buggee
heather@splashesofhope.org
info@splashesofhope.org
Phone (631) 424-8230
Web: www.splashesofhope.org

Stony Brook University Hospital
School Re-entry Program
HSC T 11 Room 020
Stony Brook, NY 11794-8111
Phone (631) 444-7521
Web: www.schoolreentry.com

Sunrise Day Camp/Friedberg JCC
15 Neil Court
Oceanside, NY 11572
Michele Vernon
mvernon@friedbergjcc.org
Phone (516) 766-4341 ext. 106
Web: www.sunrisedaycamp.org

SuperSibs!
660 N. First Bank Drive
Palatine, IL 60067
Toll Free: (866) 444-SIBS (7427)
Web: www.supersibs.org

The Starlight Children's Foundation
5757 Wilshire Boulevard, Suite M-100
Los Angeles, CA 90036
Phone (800) 315-2580
Web: www.starlight.org

Time For Teens, Inc.
Laraine Gordon
P.O. Box 552
Southampton, NY 11969
laraine@larainegordon.com
Phone (631) 338-7258
Web: www.time4teens.org

Visiting Nurse Service and Hospice of Suffolk
505 Main Street
Northport, NY 11768
Marguerite Metzendorf, L.C.S.W.
mmetzendorf@vnshs.org
Phone (631) 261-7200, ext. 338
Web: www.visitingnurseservice.org

APPENDIX F

Hematologic Disorders Resources

www.aamds.org

This is the website for the Aplastic Anemia and MDS International Foundation which helps fight bone marrow failure diseases through support and research.

www.ascass.org

This is the website for the American Sickle Cell Anemia Association which provides comprehensive information and services for families at risk for sickle cell disease.

www.campsunshine.org

Family camping programs in Maine for children with life threatening diseases including hematologic disorders.

www.caringbridge.org and www.carepages.org

Free websites for networking that are available to patients, parents and families. These sites are a great way to keep in touch with loved ones.

www.cec.sped.org

This is the website for The Council for Exceptional Children which is an international professional organization for educators working with exceptional children of all distinctions. It provides information about effective practices and ways to advocate for children with varying needs. There is an office of the Council for Exceptional Children maintained in most states across the country; the main office is in Reston, VA.

www.choa.org/sicklecell

This is the website for the Children's Healthcare of Atlanta Pediatric Hospital; a fact sheet and videos about sickle cell disease are available through this website for school personnel.

www.dbafoundation.org

This site provides information specifically about Diamond Blackfan Anemia.

www.diamondblackfananemia.com

This website provides information about Diamond Blackfan Anemia that has been gathered from many different sources on the web.

www.ed.gov/about/offices/list/ocr/transition.html

The website of the U.S. Department of Education provides an online pamphlet that explains the rights and responsibilities of students with disabilities who are preparing to attend postsecondary schools. This pamphlet also explains the obligations of a postsecondary school to provide academic accommodations, including auxiliary aids and services, to ensure that the school does not discriminate on the basis of disability.

www.fctd.info

This is the website for the Family Center on Technology and Disability which provides educators and parents with information and resources pertaining to assistive and instructional technologies.

www.heath.gwu.edu

The HEATH Resource Center is an online national clearinghouse of information about postsecondary education (college and vocational programs) for individuals with disabilities.

www.holeinthewallgang.org

This is the website for a camp in Ashford, CT for children and teens with serious health conditions including hematologic disorders. The camp is free-of-charge and sessions run throughout the summer months.

www.mayoclinic.com/health-information/

This website for the Mayo Clinic includes a "Health Information" directory that provides fact sheets for a multitude of disorders and diseases. Information can be obtained about sickle cell disease as well as other hematologic disorders.

www.ncset.org

This is the website for the National Center on Secondary Education and Transition (NCSET) which coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for students with disabilities.

www.ncwd-youth.info

This is the website for the National Collaborative on Workforce and Disability (NCWD). The Youth and Family Guide available at this site provides information about employment laws, services and programs for youth with disabilities. Many additional resources are available at this site.

www.nichcy.org

This is the website for the National Dissemination Center for Children and Youth with Disabilities (NICHCY). This site provides disability –related information as well as state-specific referral information for children from birth to age 22. Information is available at this site in English and Spanish.

www.pacer.org

This is the website for the Parent Advocacy Coalition for Educational Rights (PACER Center). The PACER center is based in Minnesota and staffed by parents. The organization's goal is to improve the lives of children and young adults with disabilities and their families by providing a variety of services and web-based resources. Topics addressed at this website include securing a free and appropriate education for students of all ages with disabilities.

www.transitioncoalition.org

The Transition Coalition provides online information, support, and professional development on topics related to transitioning students with disabilities from school to adult life.

www.victoryjunction.org

A summer camp for children with health issues. It is offered in two locations: Randleman, NC and Kansas City, KS.

APPENDIX G

Scholarships

The list of scholarships below is not comprehensive and not necessarily up-to-date. It is provided as a starting point for families and members of hospital-based school support teams who are interested in investigating available scholarships. The requirements and particulars for scholarships change frequently so it is important to gather current information about programs and applications. This information is generally available at each foundation's or organization's website.

[American Cancer Society](#)

800-227-2345

College scholarships to survivors in various states.

[Andre Sobel River of Life Foundation](#)

310-276-7111

An award of \$5,000 and honorable mentions of \$1,000 are given to United States citizens who are survivors and under the age of 21.

[Beyond The Cure Scholarship](#)

The National Children's Cancer Society

[Brain Tumor Foundation for Children, Inc.](#)

404-252-4107

Financial assistance and scholarships for survivors of pediatric brain tumor or spinal cord tumors. Applicants must be Georgia residents.

[Cancer Federation, Inc.](#)

951-849-4325

info@cancerfed.org

P.O. Box 1298

Banning, CA 92220

Scholarships are for biology majors interested in research. The scholarships are to various colleges and universities.

[Cancer Survivors' Fund](#)

281-437-7142

The mission of the organization is to provide scholarships and assistance for medical expenses to those diagnosed with cancer, receiving treatment for cancer or in remission, to give them a new purpose and meaning in life. The application and criteria are both online.

[Carolyn's Compassionate Children](#)

E-mail: childrencc@aol.com

A college-scholarship committee selects recipients based on personal character, financial need, successful completion of high school and community service. Awards are \$1,000 to be used for college education.

[Financial Aid Information Page](#)

This is a comprehensive guide to getting scholarship information but is not exclusive to cancer patients. It offers you a free search as well as basic financial information.

[Jay's World Childhood Cancer Foundation Inc.](#)

516-889-0583

The scholarship is awarded to a person who has been cured of cancer, in remission or able to attend college while in treatment and must be a resident of New York.

[Michael A. Hunter Memorial Scholarship](#)

Two \$5,000 scholarships are awarded to leukemia patients or children of a non-surviving leukemia patient.

[National Collegiate Cancer Foundation](#)

717-215-0943

One-thousand-dollar competitive awards are given based upon four criteria: financial need; quality of essay and recommendations; displaying a 'will-win' attitude; and overall story of cancer survivorship.

[Pacific West Cancer Fund](#)

320 Andover Park East, Suite 275

Seattle, WA 98188

Stephanie Cunningham, Donald Traver (fund administer)

The fund has no Web site, but the financial-aid office at any college or university should be able to provide information on this scholarship.

[Patient Advocate Foundation](#)

800-532-5274

This site has criteria and a downloadable application for a \$5,000 annual scholarship for cancer survivors.

[Pediatric Brain Tumor Foundation](#)

The foundation offers scholarships for brain tumor survivors.

[SCAPON Childhood Cancer Survivor Educational Scholarship](#)

909-558-8400

Recipient must be diagnosed with cancer before age 21 and a resident of Southern California. The award is given through the Southern California chapter of the Association of Pediatric Oncology Nurses (SCAPON).

[Scholarship Resource Network](#)

Offers a free search for scholarships with a database of more than 8,000 programs.

[Special Love, Inc.](#)

540-667-3774

Recipients must be past and/or current recipients of programs sponsored by Special Love, Inc. in the Mid-Atlantic region.

[Stephen T. Marchello Scholarship Foundation](#)

303-886-5018

Awards up to \$2500 in scholarships to one or more survivors of childhood cancer. The application can be found online.

[SuperSibs!](#)

866-444-7427

This site has criteria and application for two \$5000 scholarships to be given to siblings of childhood cancer survivors.

[The Ashley Foundation, Inc.](#)

301-694-6414

The criteria and application are available at this site. The scholarship is for Maryland residents.

[The Ryan Mullaly Second Chance Fund](#)

609-737-1800

Candidates must be United States citizens who were diagnosed with cancer between the ages of 13 and 20.

[The SAMFund](#)

On-line inquiry about grants and scholarships. The SAMFund assist young adults transitioning into the adult world by providing financial assistance.

[The Ulman Fund For Young Adults](#)

888-393-3865

This site offers scholarship information specific to cancer survivors.

[Tim & Tom Gullikson Foundation](#)

1-888-GULLIKSON

Scholarships for brain tumor patients/survivors and/or children of brain tumor patients/survivors.

[Young Cancer Survivor Scholarship Program](#)

800-877-1710, Ext. 221

Sponsored by the American Cancer Society. The information and application for the renewable \$1000 scholarship for Michigan and Indiana residents is on the ACS Web site.

APPENDIX H

Glossary of School-Related Terms

Due Process

An appeal that can be initiated by either the parent or the school to take a matter before an impartial hearing officer when there is a disagreement about whether special education services are needed or appropriate to insure a free and appropriate public education (FAPE). The request for a hearing must be done in writing and mailed to the Board of Education.

ETR: Evaluation Team Report

Report generated by the multi-factored evaluation conducted to assess the student's eligibility for services. The report is shared with the parents and all team members at the eligibility meeting.

FAPE: Free and Appropriate Public Education

Special education and related services provided in conformity with the Individual Education Plan (IEP) and without any charge to the parent.

Home-Based Instruction

Individualized education services provided to a child with a condition that prevents the child from attending school on a regular basis. In some states the child must be certified to receive special education services in order to receive home-based instruction. The number of hours of home-based instruction provided per week varies significantly from state to state. In addition, there is geographical variation in the terms used to describe home-based instruction. Instruction provided by the school system in a student's home may also be referred to as "homebound" or "home" instruction.

IDEA: Individuals with Disabilities Education Act

IDEA is the federal law that provides for all children to have a free and appropriate education. The law was enacted in 1975, reauthorized in 1997, and updated in 2004. The law requires every school district to identify, evaluate, and serve children with special education needs.

IEP: Individualized Education Plan

A plan developed by the school district and parents to meet the unique educational needs of a child with a handicapping condition. The IEP team must meet at least once a year to review and renew the education plan.

MFE: Multi-factored Evaluation

An evaluation process conducted by a team of professionals after written consent is provided by the parents. The team may include teachers, psychologists, parents, therapists, or other specialists. After evaluation the team will meet to discuss the child's eligibility for special education services. The evaluation must be repeated every three years.

OHI: Other Health Impaired

Condition which causes limited strength, vitality or alertness that results in limited alertness with respect to the educational environment. The condition must have an adverse effect on the child's educational performance to qualify for services. Children with cancer are generally eligible for special education services under the OHI designation.

Prior Written Notice

A written notice (form) from the school district to let the parents know of any recommended change in special education status. The notice must be provided to the parents to inform them of the plan when the school wants to evaluate or refuses to evaluate. If the parents disagree with the notice they may file due process to take the matter to hearing.

Related Services

Transportation and any developmental, corrective, or supportive services that are identified on the child's IEP and are necessary to allow the child to benefit from educational services. Examples of related services are door-to-door transportation, speech and hearing services, occupational therapy, or school nursing services.

Response To Intervention (commonly abbreviated RTI)

A method of academic intervention designed to provide early, effective assistance to children who are having difficulty learning.

Section 504

Section 504 of the Rehabilitation Act of 1975 is a civil rights law prohibiting discrimination against individuals with disabilities. Section 504 ensures that children with disabilities have equal access to an education. These children may receive accommodations and modifications.

Special Education

Specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability and prepare them for further education, employment, and independent living.

APPENDIX I

Annotated Bibliography

School Issues for Students with Cancer

Barerra, M., Shaw, A., Speechley, K., Maunsell, E., & Pogany, L. (2005). Educational and social late effects of childhood cancer and related clinical, personal, and familial characteristics. *Cancer, 104*, 1751-1760.

Retrospective, population-based study of 800 cancer survivors, ages 6-16, and 923 matched controls. Cancer survivors had significantly poorer educational outcomes, as defined by increased certification as learning disabled or special education, increased failed or repeated grades, and below average grades in school. Survivors were also more likely to have no close friends or confidants.

Bessell, A. (2001). Children surviving cancer: Psychosocial adjustment, quality of life, and school experiences. *Exceptional Children, 67*, 345-359.

Descriptive study of 51 cancer survivors between ages 8 – 17. Quantitative assessments revealed anxiety in children and difficulties in psychosocial adjustment in the areas of scholastic competence, emotional stability, and social competence. Qualitative results revealed that students who repeated a grade were particularly concerned with their academic performance and peer relationships. Homebound instruction was reported to be academically inadequate and socially isolating.

Butler, R. W., Sahler, O. J. Z., Askins, M. A., Alderfer, M. A., Katz, E. R., Phipps, S., & Noll, R. B. (2008). Interventions to improve neuropsychological functioning in childhood cancer survivors. *Developmental Disabilities Research Reviews, 14*, 251-258.

Reviews the identification of neurocognitive deficits in patients treated for pediatric cancer that involved CNS disease and/or treatment. Describes potential beneficial effects of stimulant medication and psychologically based brain injury rehabilitation efforts, including on-treatment schooling and reentry, within the survivor population.

Daly, B. P., Kral, M. C., & Brown, R. T. (2008). Cognitive and academic problems associated with childhood cancers and sickle cell disease. *School Psychology Quarterly, 23*(2), 230-242.

Provides a review of the research related to cognitive aspects of pediatric cancer and sickle cell disease and offers science-based practice recommendations of relevance to school psychologists.

Gartin, B. C., & Murdick, N. L. (2009). Children with cancer: School related issues. *Physical Disabilities: Education and Related Services, 27*(2), 19-36.

Discusses the research findings on medical, physical, and cognitive issues that students treated for cancer may encounter in their search for normalcy within school. Includes a checklist for educators to help prepare them for teaching a child with cancer.

Gerhardt, C. A., Dixon, M., Miler, K., Vannatte, K., Valerius, K. S., Correll, J., & Noll, R. B. (2007). Educational and occupational outcomes among survivors of childhood cancer during the transition to emerging adulthood. *Journal of Developmental and Behavioral Pediatrics, 28*(6), 448-455.

Data collected from young adult survivors, parents, and matched peers. Survivors and their peers were similar on measures of scholastic and occupational self-concept, academic competence, grades, graduation rates, current employment status, and plans to attend college. Survivors were more likely to report repeating a grade and having more school absences. Severity of late effects was negatively correlated with maternal report of academic competence, self-reported school performance, and high school graduation rates.

Harris, M. S. (2009). School reintegration for children and adolescents with cancer: The role of school psychologists. *Psychology in the Schools, 46*(7), 579-592.

Presents a model whereby successful school reintegration is promoted by consultation between children or adolescents, parents and/or caregivers, school personnel, and health professionals. The article describes the model's application to school psychologists' work and provides checklists to help guide school psychologists' intervention throughout the school reintegration process.

Hoffman, R. I. (Ed). (2012). *Educating The Child With Cancer, A Guide for Parents and Teachers*, 2nd ed. Kensington MD, USA: American Childhood Cancer Organization (acco.org).

Book written to help families and teachers cope with all aspects of educating the child with cancer, covering learning issues from infancy through adulthood.

Katz, E. R., & Madan-Swain, A. (2006). Maximizing school, academic, and social outcomes in children with cancer. In R. T. Brown (Ed.), *Comprehensive Handbook of Childhood Cancer and Sickle Cell Disease: A Biopsychosocial Approach* (pp. 313-338). NY: Oxford University Press.

Chapter discusses the potential risk factors of cancer on learning and school performance, as well as interventions to maximize school and social outcomes. Presents guidance for assisting children with cancer through the various phases of school intervention: (a) initial diagnosis, hospitalization, and homebound instruction, (b) preparing for return to school, (c) returning to school, (d) early and long-term follow-up, as well as (e) disease progression and death.

Katz, E. R., Varni, J. W., Rubenstein, C. L., Blew, A., & Hubert, N. (1992). Teacher, parent, and child evaluative ratings of a school reintegration intervention for children with newly diagnosed cancer. *Children's Health Care, 21*(2), 69-75.

Forty-nine children, newly diagnosed with cancer, received comprehensive school reintegration consisting of supportive counseling, educational presentations, systematic liaison between the hospital and school, and periodic follow-ups. Subjective evaluations of children, parents, and teachers were very positive, providing support for the social validity of the school reintegration approach for children with newly diagnosed cancer.

Mitby, P. A., Robison, L. L., Whitton, J. A., et al. (2003). Utilization of special education services and educational attainment among long-term survivors of childhood cancer. *Cancer, 97*(4), 1115-1126.

Data from CCSS sample of over 12,000 survivors and 3400 healthy siblings. Found that special education use was associated significantly with CNS-directed treatment. However, survivors of all the major childhood cancer diagnoses utilized these services more often compared with siblings, including survivors for whom CNS treatment is rarely, if ever, administered. Survivors of all cancer diagnoses used special education services at an increased rate due to missed school. Survivors of leukemia, CNS tumor, non-Hodgkins lymphoma, kidney cancer, and neuroblastoma showed significant increased use of special education services due to low test scores. Survivors of leukemia, CNS tumors, non-Hodgkins lymphoma, and neuroblastoma were significantly less likely to complete high school compared to their siblings.

Moore, J. B., Kaffenberger, C., Goldberg, P., Oh, K.M., & Hudspeth, R. 2009). School reentry for children with cancer: Perceptions of nurses, school personnel, and parents. *Journal of Pediatric*

Nurses and school personnel performed few services to facilitate school reentry for children with cancer even though both groups rated their services as moderately helpful. Parents agreed with nurses and school personnel that these professionals performed few services to assist children in reentering school.

Nathan, P. C., Sunita, K. P., Dilley, K., Goldsby, R., Harvey, J., Jacobsen, C., et al. (2007). Guidelines for the identification of, advocacy for, and intervention in neurocognitive problems in survivors of childhood cancer. *Archives of Pediatric Adolescent Medicine, 161(8)*, 798-806.

Reviews the risk factors for the development of neurocognitive sequelae and describes the expected pattern of these disabilities. Presents recommendations for the screening and management of neurocognitive late effects and outlines important areas of school and legal advocacy for survivors with disabilities. Also lists resources that can guide patients and parents as they face the long-term neurocognitive consequences of cancer therapy.

Prevatt, F. F., Heffer, R. W., & Lowe, P. A. (2000). A review of school reintegration programs for children with cancer. *Journal of School Psychology, 38(5)*, 447-467.

Reviews the literature on school reintegration programs for children with cancer. Discusses the importance of school attendance, the effects of cancer on children's social and academic adjustment, and difficulties returning to school. Types of reintegration programs reviewed included: school personnel education programs, peer education programs, and comprehensive programs.

Rey-Casserly, C., & Meadows, M. E. (2008). Developmental perspectives on optimizing educational and vocational outcomes in child and adult survivors of cancer. *Developmental Disabilities Research Reviews, 14*, 243-250.

Review article that discusses the neurodevelopmental and neurocognitive challenges faced by survivors at the early childhood, middle childhood, adolescent, and emerging adulthood stages. The authors review different types of interventions (cognitive rehabilitation, educational/vocational interventions, pharmacological interventions, psychotherapeutic interventions) and how these can contribute to optimal functioning in survivors of childhood ALL and brain tumors.

Searle, N., Askins, M., & Bleyer, A. (2003). Homebound schooling is least favorable options of continued education of adolescent cancer patients: A preliminary report. *Medical Pediatric Oncology, 40*, 380-384.

Small, qualitative study involving semi-structured interviews to assess student, teacher and parent opinion concerning students' academic achievement and attitudes toward school. Concluded that homebound instruction, hospital-based instruction, and community school attendance may be equivalent for "fully engaged students" but homebound instruction is particularly detrimental for "not fully engaged" students. Asserts that homebound instruction is best only as a very short transition period between hospital-based instruction at diagnosis and community school attendance.

Trask, C. L., Greene Welch, J. J., Manley, P., Jelalian, E., & Schwartz, C. L. (2009). Parental needs for information related to neurocognitive late effects from pediatric cancer and its treatment. *Pediatric Blood Cancer, 52*, 273-279.

Reports findings based on questionnaire responses from 90 parents regarding their knowledge of and need for information regarding neurocognitive late effects. Parents of children who received cranial radiation reported being well informed about neurocognitive late effect whereas parents of children who received chemotherapy reported wanting more information about these late effects.

Vance, Y. H., & Eiser, C. (2002). The school experience of the child with cancer. *Child: Care, Health & Development*, 28, 5-19.

Reviews the literature investigating school absence, behavior problems, and social relationships of children with cancer upon return to school. Also reviews interventions aimed at promoting successful school re-entry for children with cancer and increasing classmates' and teachers' understanding of childhood cancer.

APPENDIX J

Annotated Bibliography

School Issues for Students with Hematologic Disorders

Bonner, M.J., Hardy, K.K., Ezell, E., & Ware, R. (2004). Hematological disorders: Sickle cell disease and hemophilia. In R. T. Brown (Ed.), *Handbook of Pediatric Psychology in School Settings* (pp. 241-261). NJ: Lawrence Erlbaum Associates.

Provides a biomedical description of sickle cell disease and hemophilia, research findings pertaining to neurocognitive and psychosocial correlates of these diseases, and recommendations for school-related intervention.

Day, S. & Chismark, E. (2006). The cognitive and academic impact of sickle cell disease. *The Journal of School Nursing*, 22(6), 330-335.

Reviews the central nervous system complications and academic impact associated with sickle cell disease. Implications for school nursing practice are discussed.

Koontz, K., Short, A.D., Kalinyak, K., & Noll, R.B. (2004). A randomized, controlled pilot trial of a school intervention for children with sickle cell anemia. *Journal of Pediatric Psychology*, 29(1), 7-17.

Examines the feasibility and efficacy of a school intervention program that included written information, a teacher in-service, and a peer in-service provided to schools regarding medical issues associated with sickle cell disease. Participants who received the intervention demonstrated greater knowledge about sickle cell disease and teachers reported higher consumer satisfaction when compared to a control group who received routine services.

Peterson, C.C., Palermo, T.M., Swift, E., Beebe, A., & Drotar, D. (2005). Assessment of psycho-educational needs in a clinical sample of children with sickle cell disease. *Children's Health Care*, 34(2), 133-148.

Reports on the use of a needs assessment tool to identify the functional academic needs and learning concerns in a sample of children with sickle cell disease.

Rennie, K.M. & Panepinto, J.A. (2008). Sickle cell disease. In C.L. Castillo (Ed.), *Children with Complex Medical Issues in Schools: Neuropsychological Descriptions and Intervention* (pp. 367-378). NY: Springer.

Provides information on the medical issues and treatments associated with sickle cell disease and presents a case study, with results from neuropsychological evaluation and recommendations for classroom modifications and accommodations.

Schatz, J. (2004). Brief report: Academic attainment in children with sickle cell disease. *Journal of Pediatric Psychology*, 29(8), 627-633.

Compared children with sickle cell disease to a group of healthy children from the same community on indices of academic attainment and academic achievement. Higher rates of attainment problems were found in children with sickle cell disease relative to peers. Cognitive and academic achievement tests were found to be useful predictors of functional school outcomes.

Schatz, J., Brown, R.T., Pascual, J.M., Hsu, L., & DeBaun, M.R. (2001). Poor school and cognitive functioning with silent cerebral infarcts and sickle cell disease. *Neurology*, 56, 1109-1111.

Examines the education attainment and neuropsychological deficits in children with sickle cell disease and silent strokes. Compared to children with sickle cell disease who had no silent strokes, children with silent strokes had twice the rate of school difficulties; they also had high rates of poor educational attainment and cognitive deficits. The findings suggest that poor school performance in children with sickle cell disease is one indicator of silent strokes.

Schatz, J. & Puffer, E. S. (2006). Neuropsychological aspects of sickle cell disease. In R. T. Brown (Ed.), *Comprehensive Handbook of Childhood Cancer and Sickle Cell Disease: A Biopsychosocial Approach* (pp. 449-470). NY: Oxford University Press.

Chapter discusses the biological and environmental sources of neurological effects in sickle cell disease, as well as primary, secondary, and tertiary prevention strategies to mitigate neurocognitive effects from the disease.

APPENDIX K

Sample School-Related Letters and Forms

Letter to Family at Diagnosis

Dear Parent/Guardian,

The Pediatric Hematology/Oncology team recognizes that your family is going through a stressful time. Your child will be receiving excellent medical care. Our team is equally committed to providing you and your family support and guidance through this new and challenging world. The School Intervention Program is dedicated to addressing your child's educational and school issues. From the day of diagnosis, our team is working to return your child to school as quickly as possible. In most instances, this will be several weeks to months. The purpose of this letter is to inform you what services are offered by the School Intervention Program, and what you can expect to happen over the next few days, weeks and months.

First, you will be asked to sign a consent form by a member of the Pediatric Hematology/Oncology team. This could be a doctor, nurse practitioner, or child life specialist. The consent form will give the School Intervention Team permission to contact your child's school to discuss his illness, and how it will impact school.

You will be contacted by the School Intervention Coordinator in person if your child is in the hospital, or by phone if not. Information about your child and his/her school will be collected, and we will then contact the school on your behalf.

The team will inform your child's school that your child is under our care, and will discuss what accommodations your child will need while undergoing treatment. If your child will not be returning to school for at least a few weeks, the School Intervention liaison will arrange for home-based or hospital-based instruction. We will also offer your child's school and teacher(s) ideas to help your child stay connected to his/her classmates. Depending upon the age of your child, this could be via cards, email, "mystery guest callers" from the class, journals, or a Hero Lion who will "hold your child's seat" in the classroom during their absence.

When the medical team determines that your child is ready to return to school, the School Intervention team will meet with your child's principal, school nurse, teacher(s), school social worker/psychologists, and other educators to discuss your child's return to the classroom. This will be a time to discuss your child's diagnosis and medical issues and learning issues, in order to ensure the best transition possible back to school.

If your child is elementary school aged, we can also visit his/her classroom to prepare the classmates for your child's return. This is a fun, interactive presentation to ease the transition for both your child and his/her classmates.

The School Intervention Team is looking forward to assisting your family with any school issues, and providing your child with the best opportunity for academic success through his treatment. Please feel free to contact the School Intervention Coordinator at 631-XXX-XXXX if you have any questions or concerns.

Sincerely,

School Intervention Coordinator

Letter to School at Diagnosis

Dear Principal and Teachers,

Your student, _____, was recently diagnosed with childhood cancer, and is currently under our care at XXX Medical Center. School is one of the most important aspects of a child's life, and we invite you, your staff, and your students to join the team working to promote _____'s return to school. In an effort to provide a smooth transition to home-based instruction and re-entry into the classroom we have developed the School Intervention Program.

It is our strong belief that all children, even those with cancer and other chronic illnesses, belong in school whenever possible. School is a child's work. Providing everyday activities reinforces a child's sense of hope, belonging and accomplishment, as well as a return to normalcy. However, children with cancer need home-based instruction during the initial phases of treatment. It is best that the home-based instruction begin as soon as possible to ensure academic progress. When the medical team determines it is safe to do so, _____ will be allowed to return to the classroom. Parents and school faculty are encouraged to maintain communication to plan for her re-entry. The School Intervention Team is also available to help with the transition.

Until that time, we encourage your staff and other students to maintain active contact with _____, and continue to consider her a member of the class. We have enclosed her Lion of Courage and other ideas to keep her connected to the classroom. We ask that _____'s lion "hold her seat" in the classroom until she returns. The lion will serve as a visual reminder that _____ is still a member of the classroom community. We hope these materials will facilitate classroom discussions which will better prepare them for _____'s return.

Thank you for taking the time to review the material. Please feel free to contact the School Intervention Team at any time should you need any additional information or assistance.

Sincerely,

School Liaison

Letter Notifying Parents of Classroom Presentation

(To be sent on school letterhead)

Dear Parents,

As you may already know, one of your child's classmates has been diagnosed with cancer and has been out of school due to treatment. In order to help concerned and interested students understand their classmate's illness, we have invited the XXX Hospital's School Intervention Team to speak to your child's class on (insert date). Through age appropriate discussion, storytelling, and visual aids, the School Intervention Team can help educate students and school personnel about cancer and cancer treatment so that classmates may be more sensitive to what their friend is going through. This program will help to dispel myths and calm fears about cancer in an upbeat, fun presentation.

We invite you to participate in a preview of the program that will be presented to your child's class on (insert date). There will be an opportunity for you to meet members of the medical team, and ask questions you may have about childhood cancer.

We would also like to take this opportunity to remind you not to send your child to school if he/she has a fever, or any kind of communicable illnesses such as chicken pox. This could be potentially harmful to all students, but particularly so for children with cancer, as they are more susceptible to infection due to their treatment.

Please feel free to contact me should you have any questions.

Sincerely, School

Principal

Letter to Classmates' Parents
Following a Classroom Visit at Diagnosis

Dear Parents,

One of your child's classmates has been diagnosed and is receiving treatment for childhood cancer. The classmate's parents gave permission for the information to be shared with the children at school. Children sometimes worry when their friend is absent from school a lot or wonder why the friend looks different. Children benefit from basic information and a chance to ask questions. It also helps the children in the classroom to be understanding of the peer undergoing cancer treatment. We had a visitor from Children's Hospital in the classroom today to share basic information and answer questions. The information was presented in a developmentally appropriate way.

The following is a list of the basic information that was shared with the children:

- Cancer is NOT contagious
- A child does not do anything that causes the cancer
- Childhood cancer is very rare
- It is the treatment (chemotherapy) that makes a child look different, not the disease
- Chemotherapy is very good at destroying cancer cells but it also kills some healthy cells, causing the side effects we see or hear about
- Side effects of the chemotherapy include hair loss, fatigue, and low resistance to infection

The children were told the following ways they can be helpful:

- Wash hands often to prevent sharing germs
- Offer a play date when the friend is feeling well enough for a visit
- Send notes and well-wishes to the ill child
- Help keep the absent child up to date on the happenings at school by writing letters or making phone calls

Sincerely,

School Liaison

Physician Report on Student Health Impairment

Student name: _____ Date of Birth: _____

Parent name: _____ Phone #: _____

Address: _____

School: _____ Grade: _____

Date of Medical Examination: _____

1. Explanation of Health Impairment: _____
- _____
- _____
- _____
- _____

2. Physical condition is such that student is:

☐ UNABLE to attend school from _____ to _____

due to limitations of the medical condition.

☐ Able to attend school on a regular basis but with limitations/adjustments to the school program. Adjustments/considerations needed by the student to accommodate the medical condition include:

Signature: _____ Name: _____

Phone #: _____ Date: _____

Letter Requesting a 504 Plan

To Whom It May Concern,

_____ is a young boy diagnosed with acute lymphocytic leukemia, which is a type of cancer. _____ is medically cleared to begin kindergarten in September. Due to his medical condition, we ask that _____ be classified as 504 "Other Health Impaired" so that accommodations can be made as needed. Accommodations may include, but not be limited to, modified physical education, waiving of "no hat" policy, access to food and drink as needed, and ability to rest if fatigued. Additionally, as patients treated for leukemia are at increased risk for developing learning problems, we recommend baseline psychoeducational testing for _____.

Please feel free to contact our office at XXX-XXX-XXXX should you have any questions regarding this matter. Thank you in advance for your cooperation.

Sincerely,

School Liaison

Letter Requesting An Evaluation

To Whom It May Concern,

_____ is a young boy diagnosed with leukemia, which is a type of cancer, and is currently under my care at XXXX Hospital. Children with leukemia have chemotherapy administered directly to the central nervous system, and as a result _____ is at risk for learning difficulties. It is our strong recommendation that he receive a complete psycho-educational evaluation, so that any necessary modifications or accommodations can be made to his educational program. It would be in _____'s best interest to initiate the testing as soon as possible. Please feel free to contact me at XXX-XXX-XXXX with any questions you might have. Thank you for your cooperation in this matter.

Sincerely,

School Liaison

Letter Requesting Special Transportation

To Whom It May Concern:

_____ is a young girl diagnosed with acute lymphocytic leukemia, which is a type of cancer. She is currently under our care at XXX Hospital. We are writing to request that _____ receive special transportation to and from school via a mini bus due to her medical condition.

We thank you in advance for your cooperation in this matter. Please feel free to contact us with any questions you might have. Our office number is XXX-XXXX.

Sincerely,

School Liaison

Sample Letter Requesting No Immunizations

To Whom It May Concern,

_____ is a young girl who has been diagnosed with acute lymphocytic leukemia, which is a form of cancer. She is currently under our care at XXXX Hospital. During treatment this patient may not receive any immunizations. This is required because of the immune system suppression caused by chemotherapy during cancer treatment. Please feel free to contact our office at XXX-XXXX if you have any questions.

Sincerely,

School Liaison

Letter Requesting Intermittent Home-Based Instruction

_____ is a young girl diagnosed with sickle cell disease, which is a chronic illness. She is currently under our care at XXX Medical Center. _____'s disease requires frequent visits to the outpatient clinic and hospitalizations when she is in sickle cell crisis and her attendance at school may be intermittent. Due to her treatment and the probability of intermittent absences, we request that home-based instruction is implemented for her before the required ten days of absences to help her stay current in her school work and connected to her school, teachers and peers.

Please feel free to contact us with any questions you might have. Our office number is XXX-XXXX. We thank you in advance for your cooperation in this matter.

Sincerely,

School Liaison

Letter at Diagnosis Requesting Home-Based Instruction

To Whom It May Concern,

_____ is a young boy diagnosed with osteosarcoma, which is a type of cancer. He is currently under our care at XXX Hospital. He will be undergoing treatment which will include frequent hospitalizations, and will be unable to attend school at this time. We are therefore requesting home-based instruction for the 20XX-20XX school year to help him stay current and to prepare him for his return to school later in the year.

Please feel free to contact us with any questions you might have. Our office number is XXX-XXXX. We thank you in advance for your cooperation in this matter.

Sincerely,

School Liaison

Letter Requesting Waiver of PE Requirements

To Whom It May Concern,

_____ is currently under our care at XXX Hospital for the treatment of osteosarcoma, a type of cancer.

Due to his illness, _____ is not medically cleared to participate in gym class for the remainder of the school year (20XX-20XX). Please feel free to contact our office at XXX-XXXX if you have any questions.

Sincerely,

School Liaison

Letter Requesting Modified Physical Education Requirements

To Whom It May Concern,

_____ is a young girl diagnosed with acute lymphocytic leukemia, which is a type of cancer. She is currently under our care at XXXX Hospital. _____ is medically cleared to attend school this fall. She will, however, have some activity limitations. She will not be able to participate in strenuous physical activity or contact sports. Please feel free to contact us with any questions you might have. Our office number is XXX-XXXX. We thank you in advance for your cooperation in this matter.

Sincerely,

School Liaison

APPENDIX L

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School Issues for Siblings

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Children's Books About Siblings

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- Peterkin, A. & Middendorf, F. (illustrator). (1992). *What about me? When brothers and sisters get sick*. Magination Press. ISBN-10: 0945354495.

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