

Pathways to Success

FOR YOUTH FACING
NEUROCOGNITIVE CHALLENGES

A guide for educators and counsellors

POGO

PEDIATRIC ONCOLOGY GROUP OF ONTARIO

Pathways to Success

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A guide for educators and counsellors

SAVTI

Successful Academic and Vocational Transition Initiative
of the Pediatric Oncology Group of Ontario

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This guide is a companion publication to Pathways to Success for Survivors of Childhood Cancer, originally published in 2007. It provides information on three additional populations, including those with acquired brain injury, epilepsy, and complications from premature birth; similarities with survivors of childhood cancer were relevant to the issues faced by all these groups as they transition from high school to post-secondary education or employment. Existing material in the original publication is augmented with information about the other groups. It is intended to assist educators and counsellors as they work with youth transitioning from child to adult, from pediatric to adult care, and from high school to post-secondary education, apprenticeship, or employment.

1 Critical Transitions

Young adulthood is considered to be a particularly challenging time for most young people, as they confront the many issues associated with the transition from adolescence into adulthood. These key transitions present unique challenges to the childhood cancer survivor with a history of chronic and acute illness and medical, neurocognitive, or psychosocial late effects. Although the following was originally written with the childhood cancer population in mind, certain sections are also relevant for other populations of medically complex children who may face neurocognitive or psychosocial issues. These include children living with acquired brain injury, epilepsy, or complications stemming from a premature birth. Within the context of school, these neurocognitive and psychosocial factors can have a significant impact on learning and wellbeing. Throughout these chapters, when we refer to 'students,' we are referring to these particular groups of learners.

FROM ADOLESCENCE TO ADULTHOOD

Gaining independence and self-knowledge, developing social and personal relationships and making educational and employment decisions, can be challenging for any young adult.

When combined with the health issues some students confront, the maturational process can be particularly problematic.

THE CHALLENGE OF TRANSITION

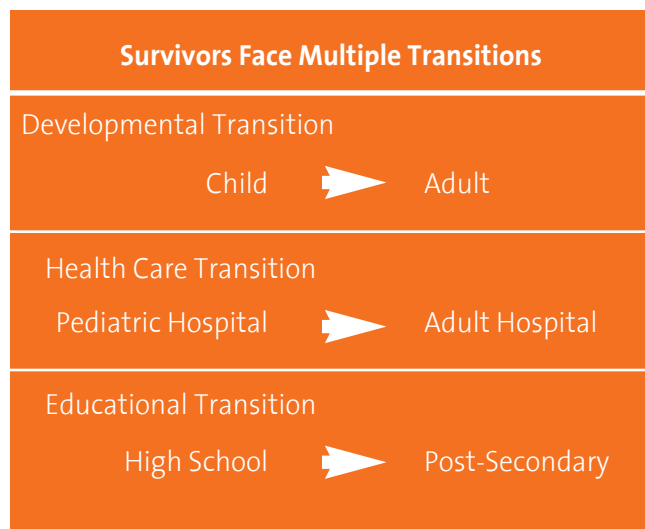
In late adolescence and early adulthood, these students must make three critical transitions:

Developmental transition: from child to adult

Health care transition: from pediatric to adult care

Educational/Vocational transition: from high school to post-secondary education, apprenticeship or employment.

Each of these transitions presents special challenges and new stresses. The adaptive mechanisms that may have worked at earlier stages, or in different situations, may not necessarily be good strategies now. These new challenges may mean that some youth who have coped successfully in the past - those with milder issues related to their diagnosis, for



example, now cope less effectively. For others, these issues may be more complex in new learning/living environments. As a result, these are critical times for intervention and present new opportunities for growth and mastery. Many skills are being learned and developed, as opportunities open up for these individuals.

“What I like about the SAVTI program is that it’s made by people who understand the medical complications and restrictions cancer survivors face in everyday life.”



“SAVTI is giving me options not to give up.”

Photographer: Leigh Tynan

DEVELOPMENTAL TRANSITION

Developmental transition means:

- Creating a stable and coherent identity
- Establishing meaningful relationships outside the family
- Establishing autonomy and independence
- Preparing educationally and vocationally for independent living

The transition from child to adult typically begins at approximately age 12 and continues into the late 20s. For students with special needs, this process may be delayed or simply take longer to complete. A number of additional issues may emerge:

Body image: the young person’s body image may present challenges to creating an identity - being ‘different’ is a significant barrier at this age.

Parental protectiveness: deeply ingrained over many years of caring for a medically fragile child, parental protectiveness may become a barrier to the transition into a more independent life.

Relationships: as a result of parental protectiveness and other factors such as social skills deficits, some young people have additional challenges establishing a circle of friends outside the family.

Dependency: illness itself creates physical dependency on parents which may impact the young person’s desire for or ability to develop autonomy.

HEALTH CARE TRANSITION

Health care transition means:

- Transitioning from family-focused to young adult-focused care
- Shifting from parental decision-making to autonomy and competence on the part of the patient
- Assuming a self-advocacy role in the shift from flexible, individualized (child-centric) treatment to a more standard treatment approach

Key considerations for students during this transition include the following:

Self-knowledge: it is important that young people have a good knowledge of their illness and treatment history and the associated risks.

Self-management: young people must develop the self-management skills required for independent functioning.

Insight

Some students living with medical conditions or the late effects of treatment may have limited knowledge of their own medical history.

For example, in a study of youth who had survived childhood cancer, only 72 percent were accurate in describing their diagnosis. Some 28 percent, therefore, did not know that they had been treated for cancer.

While the majority of survivors were aware that they had undergone chemotherapy, only 50 percent of patients who had received anthracycline - a drug that can damage the heart - were aware of this history, and only 70 percent of those who had been radiated, could identify where on their body they had received radiation.

Source:

Kadan-Lottick NS, Robison LL, Gurney JG, Neglia JP, Yasui Y, Hayashi R, Hudson M, Greenberg ML, Mertens AC: Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. JAMA 2002; 287(14): pp 1832-1839.

Medical care: for cancer survivors, annual visits to a followup (AfterCare) clinic are important to ensure that they receive the kind of medical care and surveillance they need to minimize late effects. Other populations of students with medical conditions may require ongoing treatment or follow-up appointments to manage medications, monitor status and stability.

Work must be done in the pediatric setting to prepare both the family and the survivor, for the transition into adolescence and adulthood.

EDUCATIONAL/VOCATIONAL TRANSITION

Educational/vocational transition means:

- Succeeding in more independent study
- Having fewer opportunities for feedback
- Enjoying increased freedom coupled with the need for self-management
- Adjusting to a new social situation
- Generating and adapting to a new personal support network
- Developing self-advocacy skills
- Developing a career path
- Adjusting to less teacher contact and time in class
- Meeting employer expectations (such as being on time, performing job tasks)
- Matching a job to interests, skills and abilities
- Adjusting to workplace etiquette and dynamics

The need to assume personal responsibility, make appropriate self-disclosure of health issues, advocate on his/her own behalf, and learn appropriate coping strategies, is equally relevant in the transition to post-secondary education and the workplace. Often, the post-secondary setting provides an opportunity to identify, learn about and perfect job-readiness skills.

A variety of potential problems and obstacles have been identified which may adversely affect students' success in making the transition to post-secondary education and ultimately, the workplace.

Cognitive deficits: for students with cognitive deficits, the transition from high school to post-secondary education or employment may be particularly challenging. These young people must cope with impairments of attention, processing speed, memory and, in some cases, motor skills, at the same time as they deal with the new challenges and expectations of higher education or employment. It is therefore crucial that expert advice be sought to ensure that students with special needs are placed on an appropriate educational and career trajectory, and that the required supports are both identified and available.



Expectations for achievement: low expectations of survivors can undermine their efforts to attend school or look for a job. Likewise, unrealistically high expectations, on the part of the student, parent, teacher or the counsellor, can result in frustration and discouragement. It is important that plans and goals be aligned with the young person's capabilities, and that he/she neither underestimates nor overestimates what he/she may be capable of achieving.

Motivation: the degree of motivation exhibited by the student is another significant factor in achieving successful transition. For instance, some childhood cancer survivors seem to be satisfied with the fact of survival and demonstrate little motivation to pursue career directions.

Survivors with more significant neurocognitive impairments tend to fall into this category. Other students may be so motivated that their goals exceed their realistic potential. In both of these cases, it is critical that students be presented with a range of realistic choices and opportunities that are both motivating and achievable.

While it is useful to explore each of the transitions separately, it is critical to keep in mind that they are, in fact, interdependent and do not occur in isolation. The developmental transition toward autonomy and independence, for example, will positively impact the individual's interaction with the health care system and his or her successful transition into post-secondary education or the workplace. It is important that these youth successfully negotiate developmental, healthcare and educational/vocational transitions as a critical step toward future success across all the dimensions of adulthood.

In their own voices:
The Many Faces of Survivorship

IT'S ALL ABOUT A SOCIAL LIFE

The following is adapted from recent research on SAVTI which explored the perspectives of cancer survivors and their families on academic and vocational transition. It may also be relevant for other young people who have special needs related to medical conditions, especially those that have missed substantial portions of their school experience. For many young cancer survivors in a post-secondary education setting, having a social life is a high priority. In fact, some studies have suggested that student retention has as much, if not more, to do with students' sense of connectedness to other students and the development of a social circle, than it does with interest in academics and successful program completion.

The process of treatment often involves long periods of time in the hospital or at home in isolation because of the risk of infection during chemotherapy.

"Because I wasn't allowed to go outside because of the chemotherapy, I was getting lonely sometimes."

This means that children with malignant disease may spend a lot of time alone, losing valuable opportunities for social development.

Later, after they recover, some continue to find it difficult to engage with their peers.

When survivors were asked what had been the best part of school, they spoke mainly about their friendships and social interactions. One of the main

"Well, the best part of school for me it's just the interaction with others - the social element of it."

motives expressed for returning to school was to get to know more people.

Yet for many cancer survivors, their social life was limited. Some survivors



indicated that they had been regarded as different and therefore shunned or teased.

While some parents of survivors spoke about their children's lack of friends, others expressed concern about the kinds of friends with whom their children were socializing.

Survivors interviewed by SAVTI researchers spoke optimistically about being able to fit in better at a college level because people were more mature and therefore more accepting of differences. They also hoped the fact that there were more students would mean that they would not 'stand out' as much.

Throughout these narratives, the paradox of wanting special considerations

"Well, I'm looking forward but right now, it's the transition..... I'm scared. I don't know how it's going to work out."

Survivor

within the classroom, yet not wanting to be different or singled out among their peers, was evident.

Developing a transition program that can accommodate the needs of cancer survivors and simultaneously ensure their social integration is critical.

JASMINA WAS a gifted student, attending a special program where she earned the highest grades in her class. She was diagnosed with a tumour in the central region of the brain when she was 13, in Grade 8. This region is important for memory, emotion and appetite regulation. At the time of the diagnosis, Jasmina had already begun to experience declining school performance, secondary to the impact of the tumour on the memory system in the brain.

Because the tumour was located near critical brain regions, surgery was not an option and she received focal radiation only, missing very little school. Following treatment, however, she had a severe isolated memory impairment that prevented her from being able to learn and remember new information, and interfered with her academic achievement. She also experienced dramatic change in personality and significant weight gain, both related to the anatomical location of the tumour.

These changes had a clear impact on her social and emotional well-being, and she required support from the AfterCare clinic psychologist. A neuropsychological evaluation documented the extent of her memory impairment, but also identified many areas of cognitive strength. The neuropsychologist attended a school meeting to explain the nature and extent of the challenges Jasmina was facing as a result of her medical condition. Although Jasmina's challenges did not match the traditional Ministry of Education definition of a learning disability, she was identified as having a learning exceptionality and received accommodations to allow her to circumvent her memory impairment.

Accommodations, such as open-book tests, take-home exams and the use of fact sheets, allowed her to demonstrate her knowledge and continue to excel at school, although this required far more effort on her part than it had in the past. Because she had a very supportive family and school, who were willing to make appropriate accommodations, she was close to earning her high school diploma and was exploring options for post-secondary education, but was having some difficulty in choosing options.

Jasmina was referred to SAVTI to look at appropriate options for post-secondary programs. After working on the issues and determining her interests - through a vocational assessment inventory and taking into consideration her various needs for accommodation and support - two suitable program options were identified. The SAVTI counsellor guided Jasmina through the application process, and she was accepted to a program at a local university.

Again, with the help of the SAVTI counsellor, a plan was set up to allow for Jasmina to take a reduced course load. The counsellor also assisted in contacting the accessibility staff at the university, providing support and coaching as needed, and approaching individual professors to disclose her learning needs and negotiate any required accommodations.

2 What We Can Do

Successful academic and vocational transitions are a critical issue for students dealing with medical conditions, including the effects of cancer treatment, as well as their families. Working in partnership, professionals in the medical, educational and vocational communities can give these young people the support they need to reach their personal and professional goals and achieve their highest potential.

CLOSING THE KNOWLEDGE GAP

Understanding the implications of medical conditions such as acquired brain injury, epilepsy, or complications associated with premature birth, as well as the potential late effects of cancer and its treatment, for transitioning into adulthood, is a critical first step toward supporting young people. SAVTI strongly recommends that counsellors working with these youth integrate specialized knowledge into the counselling process itself.

“Now I know I’m ready for college and I have all the information I need to make it.”

When working with students with complex medical backgrounds, qualified counsellors should have a sound knowledge of the individual’s medical history

and current profile, including current neurocognitive status. The critical challenge lies in the connection of this essential medical information, and the individual’s goals, dreams, aspirations and aptitudes, to arrive at appropriate and individualized educational and vocational goals and plans to achieve them.

STUDENTS PRESENT A COMPLEX PICTURE

Assessing the interaction among the characteristics of the young person’s particular medical condition, their medical and personal history, career and life goals and the educational and vocational opportunities available is a complex process.

In terms of childhood cancer, late effects themselves often interact in complex ways. As illustrated later in this chapter, it is possible to map late effects to reasonably predictable implications for the classroom and the workplace. However, interactions among these effects and individual characteristics - as well as with the individual’s



medical treatment, social, family, personal and educational history - will vary widely and are not predictable for any one individual.

Therefore, while an understanding of common challenges experienced by this population is essential, it does not replace a thorough assessment of the individual and his or her particular circumstances.

COUNSELLING MUST RESPOND TO UNIQUE NEEDS

At its core, the model educational and vocational counselling process developed by SAVTI for survivors of childhood cancer examines the critical questions any sound counselling process would explore.

Added to this, however, are a number of considerations that are critical to the identification of suitable pathways for this and other populations of young people.

1) What are the student's goals and aspirations?

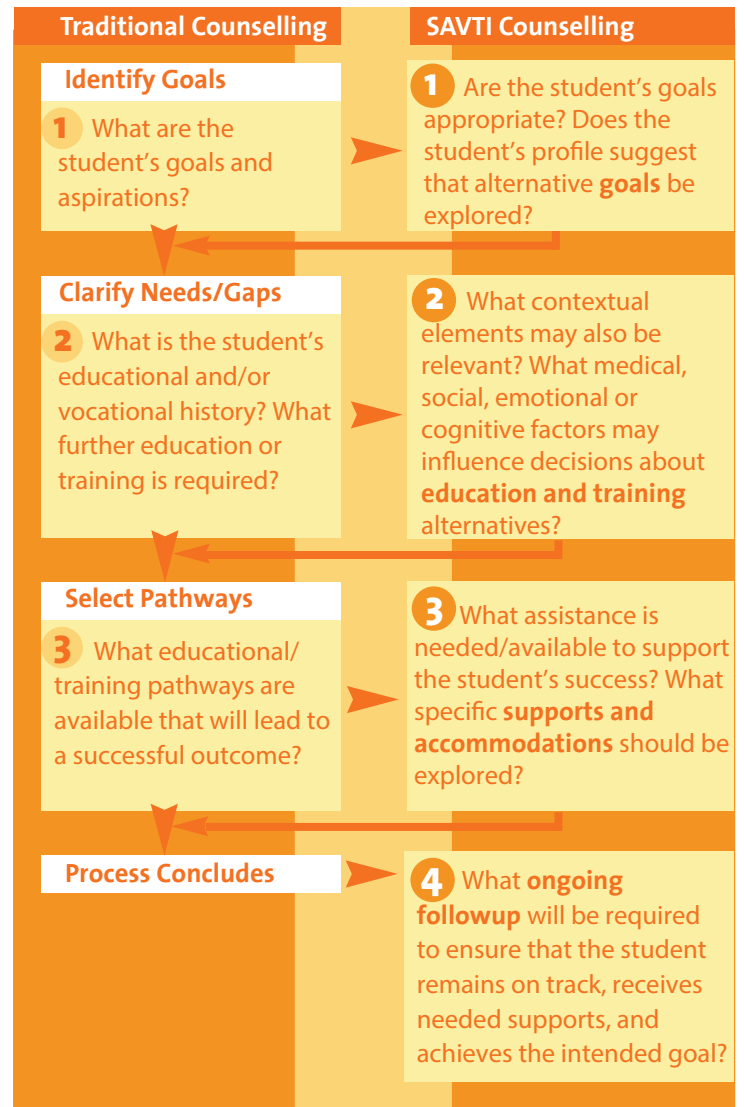
Survivors of childhood cancer may underestimate or overestimate their capabilities and options in education and later life.

As noted earlier, many survivors do not have a full understanding of their own current or previous illness and treatment history. Like all youth, they may also be unclear about the requirements and demands of a profession that appeals to them.

Here, the consequences of making an unrealistic educational or career choice can be significant, undermining the individual's ability to succeed, and potentially leading to failure and considerable reluctance to try again in a more appropriate setting.

For example, a student with motor issues - such as altered gait and balance - may be highly motivated and capable of completing the academic requirements for a career in early childhood education, but be unable to move quickly enough to ensure the safety of the children in his or her care. This issue would not become apparent in a counselling approach focused primarily on academic strengths, with a potentially devastating - and extremely discouraging - result for the student. Likewise, a student highly motivated to become an entrepreneur and academically capable of pursuing business studies, might lack the organizational skills necessary to succeed in some areas of business, or the interpersonal skills required to maintain and build customer contacts, in the absence of appropriate accommodations.

On the other hand, some students may hold inaccurate and self-defeating beliefs about the limits their earlier illness or current challenges impose, and place an inappropriate ceiling on their own dreams and aspirations.



In either case, it is a critical part of the counsellor's role to realistically assess the impact of the medical, neurocognitive, and psychosocial factors on the choice of suitable pathways at this early stage of counselling.

Optimally, young people with neurocognitive challenges from medical conditions have a neuropsychological assessment which will:

- Identify impairments such as those affecting learning, cognition and memory
- Detail medical, psychological, social, and educational and vocational background
- Explore past illness and medical treatment history
- Include a functional analysis which points to areas in which the individual may have challenges, and identifies the individual's capabilities

The following chart is provided to illustrate some of the more commonly observed characteristics of childhood cancer survivors (especially those with late effects), as well as children with acquired brain injury, epilepsy, or complications due to a premature birth; and to map out their implications for both the educational setting and the workplace. It is important to stress, however, that students may display just a few of these characteristics, or many in combination, and in varying degrees of severity. Likewise, these effects are interactive, and the resulting profile for each individual will be unique.

Challenges	Implications at school	Implications at work
Sensory <ul style="list-style-type: none"> Visual impairment CB Hearing impairment CB 	<ul style="list-style-type: none"> Student may require supports such as enlarged text, brailled text, specialized computer equipment CBP Student may benefit from an in-class note-taker CBEP Student may benefit from audio support to clearly hear the instructor CBP Student may need extra time to write tests/exams CBP Student may need voice-activated software CBEP 	<ul style="list-style-type: none"> May not be suited to occupations in which sensory abilities are critical (pilot) CBEP Safety issues arising from visual/learning impairment should be considered CBP The employee needs to take responsibility for advising the employer or supervisor of the best ways to ensure effective communication CBP
Motor <ul style="list-style-type: none"> Slow processing speed and fine motor skills CBEP Paralysis/weakness CBEP Gait/balance issues CBEP Position in space/coordinated movement CBEP Cerebral Palsy P 	<ul style="list-style-type: none"> Issues with handwriting and note-taking CBEP Issues with fine motor skills and processing speed may mask underlying understanding (for example, assess content of written work separately from spelling) CBEP Travel distances between classes on a large campus may be considered CBEP Extra time may be needed for tests/exams CBEP Issues with co-op placements (e.g. shop tech.) CBEP Student may require frequent breaks CBP Ability to take tests orally to assess understanding CBEP May require classroom on main floor or wheelchair/walker accessible environment P 	<ul style="list-style-type: none"> Match motor skills to job requirements CBEP Particularly where safety is an issue, the individual must self-identify to the employer CBEP May require an accessible environment P

Challenges	Implications at school	Implications at work
Physical Exertion <ul style="list-style-type: none"> Fatigue (especially right after an epileptic seizure; for acquired brain injury, fatigue is common early in recovery and gets better over time) CBE Easily tired CBE 	<ul style="list-style-type: none"> Scheduling may be planned to avoid large continuous blocks of class time toward the end of the day, (discuss individual needs with the student) CBE Student may require frequent breaks and snacks CBE Student may require reduced course load CBE P Note: for acquired brain injury, these issues are most problematic early in recovery; although they may persist, they typically get better over time 	<ul style="list-style-type: none"> Individual may require frequent breaks CBE Shift work should be avoided in favour of regularly-scheduled work CBE Work with frequent deadlines and pressure may not be advisable CBE
Medical <ul style="list-style-type: none"> Medical conditions CBE Required treatment CBE Required medication CBE 	<ul style="list-style-type: none"> Medications may interfere with learning and attention CBE Medical appointments and/or absences may require accommodation CBE 	<ul style="list-style-type: none"> Individual may require time off work for appointments and/or absences CBE Effect of medications should be explored with respect to both job requirements and safety issues CBE
Attention <ul style="list-style-type: none"> Distractibility CBE P Sensitivity to information overload CBE P Difficulty with multi-tasking CBE P 	<ul style="list-style-type: none"> Accommodations such as sitting at the front of class, access to a quiet workspace, having notes in advance, having a note-taker will help the student focus on instructional content CBE P Individual support CBE P Instructions should be clear and explicit CBE P Assistance may be needed to break information down into short, digestible pieces CBE P Frequent breaks CBE P 	<ul style="list-style-type: none"> Individual should avoid high-stress workplaces in which many things are happening at once and attention may need to be divided (e.g. commercial kitchen) CBE P Clear instructions and one-task-at-a-time are preferred work modes CBE P Employee must explain to the supervisor the most effective way to receive instructions, rather than hoping the supervisor will 'figure it out' CBE P

Challenges	Implications at school	Implications at work
Working Memory <ul style="list-style-type: none"> Deficits in divided attention CBE Difficulty with simultaneous retention or processing of multiple ideas/information CBE 	<ul style="list-style-type: none"> Accommodations such as sitting at the front of class, notes in advance, a note-taker CBE Clear, explicit, visual instructions CBE When writing, focus on one concept at a time (e.g. first get ideas out, then focus on spelling, grammar, etc.) CBE Multi-step math problems and reading comprehension are risk areas; focus narrowly, one task at a time, and step-by-step; make lists Use of mnemonics (e.g. for the steps of long division) CBE 	<ul style="list-style-type: none"> Written instructions are highly preferred over verbal instructions CBE The employee will need to develop the habit of consistently writing instructions/information down for later recall CBE Occupations requiring rapid fire multiple information inputs or instructions may be inadvisable (taxi dispatcher, air traffic controller) CBE
Processing Speed <ul style="list-style-type: none"> Longer time required to process information CBE Delay between question and response (verbal or written) CBE Difficulty with high rate of information input CBE 	<ul style="list-style-type: none"> Student may need to self-identify so that instructors and peers are aware and can accommodate CBE Longer test times or extended time for writing/essays may be required CBE A note taker, tape recording or similar may assist the student in reviewing content at his/her own pace CBE 	<ul style="list-style-type: none"> Individual may want to avoid occupations in which rapid response is a critical job skill (customer service representative); and occupations involving multi-tasking (e.g. executive assistant) CBE The occupation should match the individual's ability to receive/process and respond to information CBE
Memory and Learning <ul style="list-style-type: none"> Slow rate of new learning CBE Fast forgetting CBE Difficulty with rote learning CBE 	<ul style="list-style-type: none"> Activate learning by making subjects meaningful to the student CBE Rote learning (out of context) will require particular effort and support CBE Notes, mnemonics, and fact sheets CBE Recognition format tests may be more appropriate than fill-in-the-blanks CBE Writing things down and using a digital recorder may be helpful CBE Student may need to use an electronic organizer/daytimer CBE Student may require an individualized timetable CBE 	<ul style="list-style-type: none"> Occupations which require a high rate of continuous new learning/new information may be challenging CBE The employee will need to develop the habit of consistently writing instructions/information down for later recall CBE When engaging in a training program, the employee may wish to request any required accommodations CBE

Challenges	Implications at school	Implications at work
Executive Function <ul style="list-style-type: none"> Difficulty with 'follow-through' CBE Although motivated to pursue a goal/outcome, the individual may have difficulty consistently taking action CBE A separation between 'intent' and 'action' CBE 	<ul style="list-style-type: none"> Student will need good time management skills, supported by aids such as a daytimer CBE A peer or other supportive individual may help the student stay on track CBE Key assignments and homework must be diligently recorded by the student CBE Student may need large assignments broken down into smaller tasks CBE Help with managing deadlines CBE 	<ul style="list-style-type: none"> Failure to follow through on plans/schedules may cause serious employability issues if not addressed CBE Employees will need to develop exceptional time and project management skills - aids such as paper or electronic schedulers may be helpful CBE Individuals may wish to pursue occupations in which incoming workflow determines their actions, rather than adhere to a long-term plan CBE
Language <ul style="list-style-type: none"> Lower vocabulary CBE P Delays in developing more complex language CBE P Issues with speech production CBE P 	<ul style="list-style-type: none"> Multi-sensory or visual instruction may help CBE P May require support to communicate, especially when frustrated/emotional and in social situations CBE P May require speech/language pathology CBE P May have difficulty speaking clearly or choosing words CBE P May have difficulty interpreting others' body language, facial expressions, or figures of speech CBE P 	<ul style="list-style-type: none"> Individual may be suited to careers with a strong visual component CBE P
Autonomy <ul style="list-style-type: none"> Over-reliance on parents CBE P Slower transition to full adult autonomy CBE P Hesitation over decision-making CBE Difficulty performing self-care skills P 	<ul style="list-style-type: none"> With help from guidance counsellors and others, students need opportunities to develop a sense of mastery, independent of parental support CBE P Student may need explicit support in developing decision-making skills and confidence in using these skills CBE Encouragement and support may be needed to develop self-management and advocacy skills CBE P Student may need encouragement and support to develop self-care skills P It may be necessary to work directly with parents to help redefine parent-child relationships and support encouragement of autonomy CBE P 	<ul style="list-style-type: none"> Occupations which focus on carrying out established processes (purchasing agent) may be preferred over those emphasizing decision-making (project planner) CBE It is important to keep in mind that autonomy develops over time and that career decisions should not be limited by what, for most young adults, will be a successful transition to adulthood and autonomy CBE P Mentoring in the context of employment may help employees adjust to the demands of the workplace and build the confidence to act autonomously with time CBE P

Challenges	Implications at school	Implications at work
Identity <ul style="list-style-type: none"> Self-esteem CBE Anxiety about 'differentness' CBE Physical issues CBE 	<ul style="list-style-type: none"> Although it may help them in other ways, students may hesitate to self-identify for fear of being labelled CBE Anxiety about past or future illness and/or physical differences resulting from illness may also be issues as students transition into their identity as adults CBE Student may require counselling support, with particular focus on fostering social acceptance from peers CBE Help from mentors CBE 	<ul style="list-style-type: none"> Employees with low self-esteem may encounter social issues at work CBE Anxiety may also diminish an employee's overall sense of confidence CBE Employees may require counselling support and identification of specific strategies to reduce anxiety and build confidence CBE Team-building exercises may also be of benefit CBE
High-risk behaviour <ul style="list-style-type: none"> Drug use CB Drinking CB Smoking CB Unprotected sex/inappropriate sexual behaviours CB 	<ul style="list-style-type: none"> Students' interest in the development of a social circle may lead to risky behaviours CB Impulsivity and poor decision-making can lead to high risk behaviours CB 	<ul style="list-style-type: none"> Inappropriate social/sexual behaviours in the workplace may have serious legal and employment consequences CB
Mental Health & Behaviour <ul style="list-style-type: none"> Depression CBE P Anxiety CBE P Externalizing behaviours (e.g. anger management issues) CBE P 	<ul style="list-style-type: none"> Depression or anxiety may result in missed attendance, missed assignments CBE P Student may require counselling support and/or psychiatric intervention CBE P Difficulty managing emotions could lead to outbursts and impact ability to participate in classroom activities CBE P 	<ul style="list-style-type: none"> Depression and anxiety can adversely affect work performance and interpersonal relationships on the job CBE P Employees may require counselling support and/or psychiatric intervention CBE P

2) What is the student's educational and/or vocational history?

When the suitability of the student's goals and aspirations have been established, in-depth consideration of appropriate education and training pathways must be undertaken, with reference to the student's educational background, which may have included an Individual Education Plan (IEP).

Whereas a 'traditional' counselling process might focus primarily on academic results - and the academic requirements of the student's chosen educational program or career - counselling for this population requires a much deeper exploration of the context of the student's earlier medical history, and the implications of illness and late effects for future learning.

For example, a student survivor of childhood cancer may have achieved successful results in secondary school, but only with considerable extra study and struggle, and with accommodations in place as identified through the IEP. A pathway choice based on academic results alone may fail to take into account that the earlier supports may not be available, or that the rigours of a higher level academic program may be overwhelming. An important part of the counselling process, therefore, is to seek out and access the supports which may be necessary for the student to achieve success.

Similarly, it may be the case that a student is capable of completing a chosen program, but only with many accommodations and over an extended period of time. It could be that the likelihood of the student's success in the field becomes an issue, or that a variety of options within the field itself need to be explored. For example, a student who wants to become a graphic designer - but may not be suited to a high-pressure, deadline-driven agency environment - might well pursue this profession successfully in other settings or organizations that employ graphic designers.

3) What education/training pathways are available that will lead to a successful outcome?

Exploration of educational history must also be integrated with a sound understanding, not only of the academic demands of selected educational programs, but also the education environment itself and how it may impact student success.

For example, a student who struggles with fatigue may experience considerable challenges due to inappropriate class scheduling, or the physical distances required to navigate a large urban school campus. Long absences from school during treatment may have resulted in feelings of loneliness or isolation that work against social integration and may impact a student's expectations about, or experience of, a school setting.

4) Follow-up: a key consideration

Whereas the traditional counselling process may conclude with the recommendation of appropriate educational or vocational pathways, additional services and accommodations may need to be considered for these populations of young people. The effects of childhood cancer treatment may result in an 'inertia' exhibited by some cancer survivors, in addition to some youths living with the effects of a medical condition. The result is that the student, although highly motivated, and equipped with a clear plan of action, may experience considerable difficulty in taking action and following through on the steps required to institute that plan. As a result, an effective counselling process for this population must not only identify an appropriate educational or vocational pathway, but also incorporate a plan for monitoring, tracking and supporting the student to ensure that he or she remains on track, and proceeds successfully toward the completion of the academic or vocational plan.

Insight

Transitioning into post-secondary education

For some people living with the effects of childhood cancer, epilepsy, acquired brain injury, or complications of a premature birth, college and university programs will not represent a challenge.

These students, who have done well in their high school studies, can compete for places in post-secondary programs on a level playing field with their peers across the province.

For others, who fall short of acceptance by a small margin, universities and colleges may offer an opportunity to submit supplementary information or have an appeals process. The institution may consider factors, such as a period of ill health, which may have affected the student's grades. If the college or university deems it appropriate, these students may be accepted into the program of their choice, accepted into an alternative program or admitted for part-time studies.

For students who do not qualify for college or university acceptance, institutions will very often have alternative access programs available. For example, many institutions will have provisions for applicants who were home-schooled, or for mature students who did not meet admission standards. These programs provide an opportunity for those who have not yet met program requirements to demonstrate their ability to do college or university-level work.

Many colleges provide mature students the opportunity to apply to programs without a high school diploma. Students are asked to write a mature student test on which they would need to demonstrate an appropriate level of achievement. It is important to understand that each institution will have its own distinct procedures and that deadlines and restrictions may apply to these procedures.

While these processes offer some students a valuable alternate pathway

into post-secondary study, care should be taken that they not be represented as 'easy' alternate routes. In the past, some students who had not received accommodation in the elementary/secondary system were able, with the appropriate supports, to succeed at the post-secondary level. Success at the elementary/secondary level does not guarantee, however, that students have the capacity for post-secondary work.

While the selection of appropriate college and university programs is critical for all students, there are a number of additional considerations to keep in mind when working with students who have special needs.

There is a substantial shift in culture between the elementary/secondary and post-secondary systems. Whereas accommodation/modification in the elementary/secondary system often focuses on gearing the program and expectations to the student, accommodation at the post-secondary level is focused on how the student can reach program goals, rather than on alteration of the goals themselves.

Today, most students who need accommodations have received some support during their elementary/secondary school career. Because they have experienced success they may want to appear as a regular student and may not feel accommodations are necessary in the post-secondary setting.

For all students - those admitted on academic standing, those admitted on appeal, and those admitted through access programs - there are a number of additional considerations that they, and their counsellors, need to keep in mind. Ontario has many colleges and universities to choose from. For some students, choosing the institution may be as important as choosing the course of study itself. For example:

Physical needs: some students with issues of fatigue may prefer a smaller, more manageable campus. If students are considering a large campus, they should explore the transportation services that may be available.

Social preferences: some students may enjoy the benefits of a small college or university campus where they can more easily meet people and become part of a peer group. On the other hand, some students may prefer the anonymity of a larger campus where they can blend into the student population.

Autonomy: for students who require many prompts, living at home while attending college or university may be the optimal choice. Alternatively, living in residence may provide the opportunity to take an important step toward autonomy, in a safe and relatively controlled setting. In addition, these students may thrive on a smaller campus where instructors will likely know them on a personal level and provide more individual attention.

Learning style: class sizes and other variables that affect the delivery of learning may be important to some students. Those who have challenges with social skills, for example, may want to avoid courses that involve a lot of group work. On the other hand, these courses may present an opportunity to develop social skills.

Accommodations: colleges and universities provide a range of accommodations for students with special needs.

It is important to determine how each institution provides these services, as well as the availability of counselling, medical or other supports.

Each college and university in Ontario is unique. Wherever possible, students should take the opportunity to visit the campus and develop a first-hand understanding of the physical and social environment offered by each institution, in addition to its programs, facilities and services. It is clear that there is no single 'right' answer. Even students with similar interests and challenges may make different choices based on personality, social skills and/or family considerations.

In their own Voices: The Many Faces of Survivorship

SCHOOL IS HARD

The following is adapted from recent research on SAVTI which explored the perspectives of cancer survivors and their families on academic and vocational transition.

The experience of school is difficult for many survivors. Periods of missing school, cognitive difficulties, and feelings of social isolation, all contribute to a range of problems and frustrations.

Most parents interviewed described encouraging their children to participate in the regular school system as much as possible during and after treatment. The stress of keeping up with classmates in an environment that is not equipped to handle their needs,

“Grade nine was like really, really terrible for me. Because I went from like an elementary, like a public school, to a high school. It was so terrible, I would be like at the back of the class and then put like stuff on the board or whatever and I would have no idea about what to do. I would just hide from the teacher and make sure she doesn't go like.. 'Oh Susan, do you know the answer to this?' After a while, I couldn't take it anymore and I wanted to drop out.”

however, can be too difficult for many young survivors. Some survivors remain in their regular schools with extra tutoring or an educational assistant to aid them in their learning, or with home schooling by a parent, or home instruction provided by the school board. Some transfer from school to school until they find a specialized school or program that can provide the kind of support they need.

Expectations were often either too low or too high.

Educators' lack of understanding about the experiences and needs of cancer survivors was very frustrating.

Interviews revealed that a further complicating factor was that survivors and parents may not fully



inform school staff about the illness experience and need for extra help, thus jeopardizing their chances of receiving the support they need.

In addition to needing extra time to complete assignments or exams, and more individual help, survivors described to SAVTI researchers the need for encouragement. Recognizing the pressure survivors often put on themselves to succeed at school and work, parents also stressed the importance of encouraging rather than pressuring these young people.

“I think I could have used more of that (encouragement). Like I would get assignments done and hand them in, but that was it. I didn't get a good job or anything.”

It is evident throughout the narratives that teachers are a critically important influence on cancer survivors' experience of school. A teacher's knowledge of the survivor and his or her challenges is an important factor in effectively providing support. However, students cited a teacher's being 'nice' or 'likeable' as equally important.

ALEXANDER WAS DIAGNOSED with leukemia when he was 3 years old. Treatment included a relatively low dose of radiation to the whole brain and 3 years of chemotherapy. Alexander was able to attend much of junior and senior kindergarten, and all treatment was concluded by the time he entered Grade 1 at the age of 6.

Alexander was slow learning to read. He required individual tutoring and attended Reading Recovery in Grades 1 and 2. He also had particular difficulty mastering math facts in his elementary years and did very poorly in math. Alexander was generally slower than other children his age, and often didn't finish his work in school. He was also very distractible and forgetful, and was poorly organized. For example, he would forget his books at school, leave his homework or lunch at home, and would lose his hat and mittens on a regular basis. He would often start one project and then leave it to do something else. Even when he finished his homework at home, he would forget to hand it in the next day.

By the time he reached high school, Alexander was struggling to pass the math requirement and dropped from the academic to the applied stream. This was particularly hard for him because his family is highly educated and successful, and there was an implicit expectation that he would attend university and pursue a professional career. As a result, he is

very motivated to succeed and is anxious about his future. He spends 4 to 6 hours on homework each evening to meet his own high expectations. He wants to apply to university programs exclusively and has not been open to exploring alternative education or vocational options.

Alexander was referred to SAVTI to discuss his application to university, as he is not likely to be successful, based on the applied subjects he had been taking in high school. The plan will be to work on realistic options which will interest him, and be accessible, given his academic background. If he is open to applying to college, he would need a reduced course load and would require some accommodation. The SAVTI counsellor would assist him with the application process and would ensure that he link with the Disability Services in the college, once he is accepted.

HOW SAVTI CAN HELP

SAVTI provides specialized educational and vocational counselling to survivors of childhood cancer and their families. SAVTI also provides education and outreach services to professionals in the medical, educational and vocational communities. As has been demonstrated above, this same model is applicable to young people with other medical conditions that affect cognitive development and neuropsychological function.

If you are working with a young person who has survived childhood cancer, and would like to ensure that he or she receives specialized professional counselling, contact SAVTI at:

savti@pogo.ca

OR

London: 519 685 8500, ext. 52527

Hamilton: 416 592 1232, ext. 244

Ottawa & Kingston: 613 737 7600, ext. 3495

Toronto: 416 592 1232, ext. 255 & 244 **or**

Toll free: 1 855 367 7646

Other organizations which may be helpful:

Ontario Federation for Cerebral Palsy:

info@ofcp.ca

416 244 9686

1 877 244 9686 (toll free)

416 246 9122 (TTY)

Epilepsy Ontario:

info@epilepsyontario.org

905 474 9696

1 800 463 1119 (toll free)

Ontario Brain Injury Association:

obia@obia.on.ca

905 641 8877

For Youth:

www.diseaseonmysleeve.org

