

Pathways to Success

FOR SURVIVORS OF CHILDHOOD CANCER

A guide for educators, counsellors and families



POGO

PEDIATRIC ONCOLOGY GROUP OF ONTARIO

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SAVTI

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

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As educators, counsellors, health care providers and parents, we share a commitment to ensuring that every child and young adult has the opportunity to reach his or her highest potential in school and in later life.

Survivors of childhood cancer may face a variety of challenges. Yet, these remarkable young adults often draw on unique strengths which can be nurtured and developed to support their educational and vocational success.

As our understanding increases, so does our ability to effectively guide these young people as they move through critical transitions, and choose successful pathways that meet their unique needs, capabilities and aspirations.

SAVTI, through the Pediatric Oncology Group of Ontario, has developed this guide with a team of experts in both health care and education, to provide clear, straightforward answers to the questions counsellors and families ask most often about how to effectively support survivors of childhood cancer.

It is our hope that the publication of this guide will mark a critical step forward in closing the knowledge gap, removing barriers for survivors of childhood cancer and helping this important group of young people build successful and rewarding futures.

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In their own voices:
The Many Faces
of Survivorship

There is no 'typical' survivor of childhood cancer. The late effects of cancer and its treatment vary widely in type and severity, ranging from medical effects, such as heart disease, to neurocognitive deficits. These specific effects interact with social and family background, educational history, vocational goals and many other factors.

Survivors do, however, share many common perspectives, aspirations and challenges. The themes presented in this document, based on a recent study of cancer survivors and their families conducted on behalf of SAVTI, provide an important view into the lives of young cancer survivors, the 'real life' challenges they face, and the services they often want and need to support their successful transition into adult life.

- I am not a statistic..... 5**
- I can do this.....10**
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- I have goals and dreams.. 32**

Source:
An Academic/Vocational Transition Program: Perspectives of Survivors of Childhood Cancer and Their Families.
Prepared by:
Katherine M. Boydell, MHSc, PhD., Scientist, Population Health Sciences, The Hospital for Sick Children, Department of Psychiatry, and Public Health Sciences, University of Toronto.
Elaine K. Stasulis, M.A., Research Coordinator, Population Health Sciences, The Hospital for Sick Children.

1 Introduction: Survival is Not Enough

The successful treatment of childhood cancers is widely regarded as one of the ‘miracles’ of modern medicine. Survivorship, however, comes at a cost. Many survivors of childhood cancer face unique challenges that adversely affect their successful transition into adult life.

THE ISSUE: FROM SURVIVAL TO QUALITY OF LIFE

Significant advances in the treatment of childhood cancers have resulted in a dramatic increase in the rate of survivorship. In fact, more than three-quarters of children treated for cancer now survive five years or more.

As a result, the attention of care givers has broadened from the issue of survival to the longer-term effects of cancer and cancer treatment and the impact these may have on quality of life.

CANCER AND ITS TREATMENT MAY HAVE LATE AND LONG-TERM EFFECTS

In addition to the effects of cancer itself, a variety of cancer treatments – including radiation therapy, surgery, chemotherapy, bone marrow transplants, and other medicines – may cause damage to normal cells in the body, resulting in infertility, growth problems and cardiac dysfunction. A variety of emotional and psychological effects may also arise as a result of the cancer experience such as anxiety, depression, and cognitive changes.

In an educational or vocational setting, cancer survivors may experience a variety of learning challenges, including some or all of:

- Slower thinking speed
- Increased forgetfulness
- Difficulty mentally manipulating information or holding information ‘in mind’
- Inattention and distractibility
- An ‘inertia’ that makes it difficult to follow through on goals and plans



SAVTI case studies

You can deepen your knowledge of this unique student population, and the SAVTI counselling process, by reading these case studies.

Juan page 11	Stacey page 33
Jasmina page 17	Abe page 33
Alexander page 27	Teresa page 35

Social skills may also be significantly impaired, due to missing school or being ill during the formative years, which results in a variety of challenges both within and beyond the educational system.

Superimposed on this profile of complex learning challenges, young adult survivors of brain tumours may also experience:

- Persistent fatigue
- Weakness in one or more limbs
- Impaired vision or hearing
- Atypical physical characteristics

THESE EFFECTS CAN OFTEN HAVE A PROFOUND IMPACT IN LATER LIFE

The effects of cancer, and cancer treatment, can adversely affect the quality of life of young adult survivors.

In addition to medical effects, many survivors of childhood cancer have neurocognitive and psychosocial challenges which may result in:

- Low self-esteem, depression, and preoccupation with their physical condition, including a negative body image
- Poor social skills and problems with peer relationships
- Difficulty finding employment
- Failure to pursue and/or achieve in educational, apprenticeship and vocational pathways

These effects may impact family life, educational and vocational choices and opportunities, integration into the community, overall quality of life, and standard of living.

TRANSITIONS ARE CRITICAL

Under legislation, school boards are required to provide support programs within the secondary school system. Accommodations and supports also exist within post-secondary institutions. It is in the critical transition phase between these two systems that major vocational decisions must be made. While school boards provide transition planning for students with special needs (see Appendix Transition Planning: A Resource Guide), they often lack the information and knowledge to adequately plan for this unique group of students.

Thus a significant challenge exists for these adolescents and their families as they transition from the child-centered to adult-focused education and health care systems.

These young people need personalized counselling before embarking on an educational or employment path that will allow them to realize their full academic and vocational potential while ensuring that future plans are aligned with their own profile of skills, challenges and interests.

Identifying barriers

In combination, the late effects of childhood cancer treatment can create barriers to success in traditional learning or work environments. A growing body of research demonstrates, for example, that many young cancer survivors have considerable difficulty making the transition to appropriate post-secondary education or the workplace. A Canadian-led meta analysis of 9 papers examining neuro-development sequelae concluded that:

- *Adult survivors of childhood leukemia were more likely to require special education.*
- *While the rate of full-time employment for survivors who had not been radiated was similar to that of the general population, survivors who had been treated with Cranial Radiation showed greatly elevated rates of unemployment, which were twice as high for women (35.4%) than men (15.1%) [Pui et al., 2003].*
- *While estimated intelligence (WASI) was average, attention, reasoning/calculation, and reaction times were impaired.*
- *Children treated according to current, less-intensive protocols are expected to display better adult outcomes.*

Janzen L. A. & Spiegler B. J. Neurodevelopmental Sequelae of Pediatric Acute Lymphoblastic Leukemia and Its Treatment. Developmental Disabilities Research Reviews 14: 185-195 (2008)

Pathways to success: SAVTI and POGO

See Chapter 5 of this guide for more in-depth information about the programs and services provided by SAVTI, and the role played by POGO in identifying and advocating for the needs of young cancer survivors and their families.

ABOUT THIS GUIDE

This guide was developed by the Successful Academic and Vocational Transition Initiative (SAVTI) of the Pediatric Oncology Group of Ontario (POGO) to support professionals in the educational, medical and vocational counselling fields who work with survivors of childhood cancer.

Pathways to Success for Survivors of Childhood Cancer is one component of SAVTI's ongoing commitment to developing and sharing effective practices for childhood cancer survivors, building vital links with and among educational, vocational and community organizations, and ensuring that the unique needs of childhood cancer survivors are being addressed province-wide.

It is SAVTI's hope that the counselling model presented in this document may also prove beneficial for other populations. Some components of this model, for example, may be applicable to Acquired Brain Injury (ABI) survivors.

WHO THIS GUIDE IS FOR

SAVTI recommends that this guide be provided to educational, vocational and health care providers such as:

School Boards

- Guidance counsellors
- Psychologists
- Teachers
- Special Education teachers
- Department heads
- Co-ordinators of Special Education
- Superintendents of Special Education
- SEAC representatives
- Student Success teachers
- Principals

Colleges and Universities

- Counsellors
- Psychologists
- Disability consultants
- Accessibility/Special Needs department staff

Community Agencies

- Employment counsellors
- Rehabilitation counsellors

Health Care Providers

- Family doctors
- Cancer AfterCare clinic staff

The guide will also be of value to parents/guardians and cancer survivors who want to add to their knowledge of survivorship issues and the variety of services and supports available to them in Ontario.

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Ms. Barbara Dyce

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PRINCESS MARGARET HOSPITAL

Mr. Frank Emmerson

EMMERSON COMMUNICATIONS

Dr. Corin Greenberg

PEDIATRIC ONCOLOGY GROUP OF ONTARIO

Dr. Mark Greenberg

PEDIATRIC ONCOLOGY GROUP OF ONTARIO

Ms. Ann Klinck

CHILDREN'S HOSPITAL, LONDON HEALTH SCIENCES CENTRE

Ms. Robyn Lange

GEORGE BROWN COLLEGE

Ms. Susan Portner

PEDIATRIC ONCOLOGY GROUP OF ONTARIO

Dr. Georgia Quartaro

GEORGE BROWN COLLEGE

Mdm. Lucie Quesnel

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Photos courtesy of the AfterCare clinics at Hamilton Health Sciences Centre, Children's Hospital, London Health Sciences Centre, SickKids, Toronto, Windsor Regional Hospital and SAVTI participants & parents.

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In their own voices:

The Many Faces of Survivorship

I AM NOT A STATISTIC

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

As a group, childhood cancer survivors exhibit a variety of physical, medical, psychosocial, neurocognitive and social characteristics that make them unique as a general population. Within this constellation of characteristics, however, there is great diversity of symptoms and lived experiences. The diversity among

"For me, personally, concentrating and retaining knowledge was and still is a huge factor....I have a hard time retaining knowledge. That's probably the most difficult thing. My memory is just shot."

survivors of childhood cancer – in terms of the effects of their illness and the experiences that follow from them – necessitates close attention to the particular attributes of each survivor's individual profile.

For the survivors who participated in the SAVTI study, experiences with cancer resulted in a range of invisible and visible effects highlighting the distinctive nature of each survivor's challenges and needs. Some survivors suffered from neurocognitive effects such as short-term memory loss, for example, and had difficulties in reading, writing and mathematics. The degree and type of difficulty varied, and impacted their academic experiences in different ways.

On a more visible level, some survivors may experience difficulties with mobility because of problems with their gait or balance. This affects their ability to keep up with their peers, get to class on time and participate in some kinds of group activities.

Others experience permanent hair loss and, because of their smaller physical stature, may appear

"I have like a scar in the back of my head and stuff like that and you know, I just learned to forget about it, but others can't seem to do the same."

years younger than they are. Family members interviewed by SAVTI researchers felt that their child's youthful appearance may have been a factor in failing to get job offers,



Photograph: CLICK Photography

despite numerous interviews. For some survivors, their physical appearance meant that they were a target of ridicule or perceived rejection from others. Survivors who felt that they looked more 'normal' conceded that socializing was probably easier for them than their peers.

It is critical to keep in mind that two young people with the same illness and treatment can nonetheless present with very different problems, in both type and severity. Medical history is not

a reliable predictor of the very individual strengths and challenges young cancer survivors may have in later life.

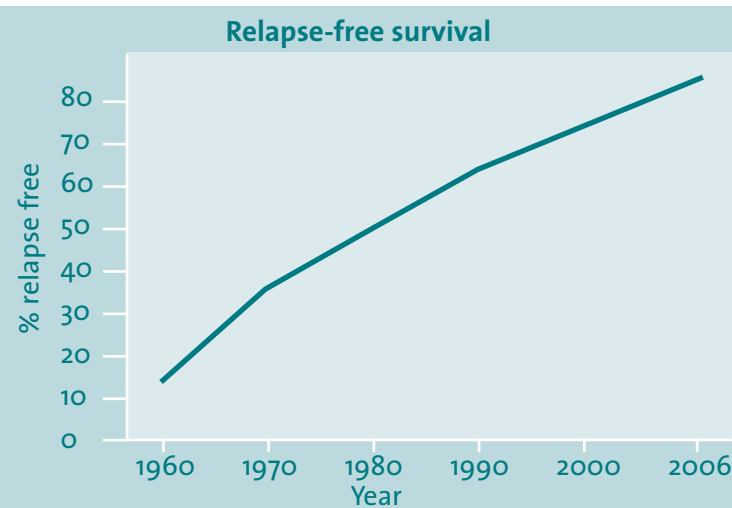
"Something that I have a hard time with still, is motivation. I have a hard time motivating myself... If I could, if I knew that I could get away with it, I think I would probably sleep all day. You know watch television and not move."

What We Know: The Challenge of Survivorship

In recent years, an expanding body of research and experience with survivors of childhood cancer has opened important windows into our understanding of long-term effects. This knowledge is a critical foundation for the development of interventions that will effectively address the needs of childhood cancer survivors.

SURVIVAL RATES: A SUCCESS STORY

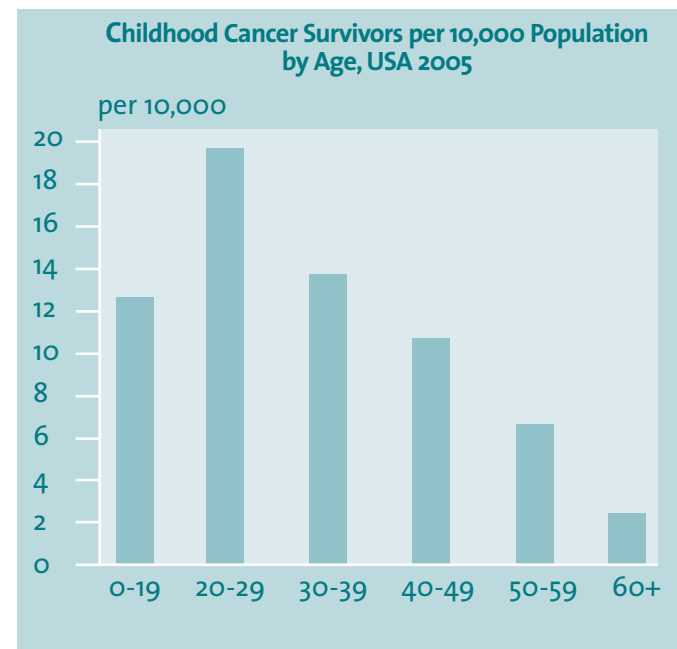
Prior to the advent of modern treatment, childhood cancer was inevitably and rapidly fatal. However, current survival rates are more than 80 percent.



Projected incidence: 1:400 adults 20–45 will be a survivor of childhood cancer

Source: Journal of National Cancer Institute 2006:98:883

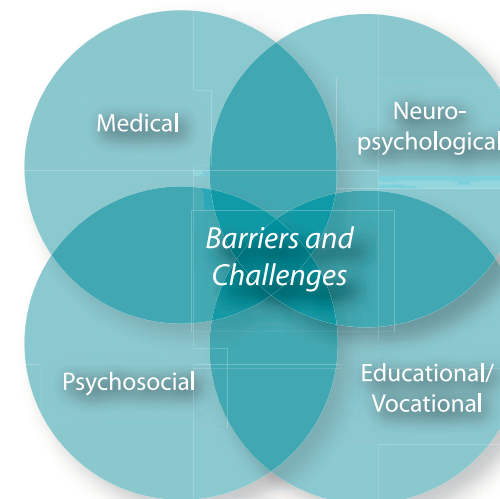
It was estimated that in January of 2005 there were a total of 328,652 childhood cancer survivors in the United States (Mariotto et al., 2009). This translates into approximately 14,000 childhood cancer survivors in Ontario or 1 in 350 adults between the ages of 20 and 45 years is a childhood cancer survivor.



Mariotto et al. Cancer Epidemiol Biomarkers Prev 2009; 18(4). April 2009

Since this is a substantial population with the potential to have a significant and increasing impact on society, it is critical that we focus our resources on:

- Identifying the late effects of cancer treatment
- Taking the lessons learned from the current cohort of survivors to inform our treatment of the next generation of patients
- Preventing, modifying or minimizing the late effects.



LATE EFFECTS MAY BE PREDICTED AND ADDRESSED

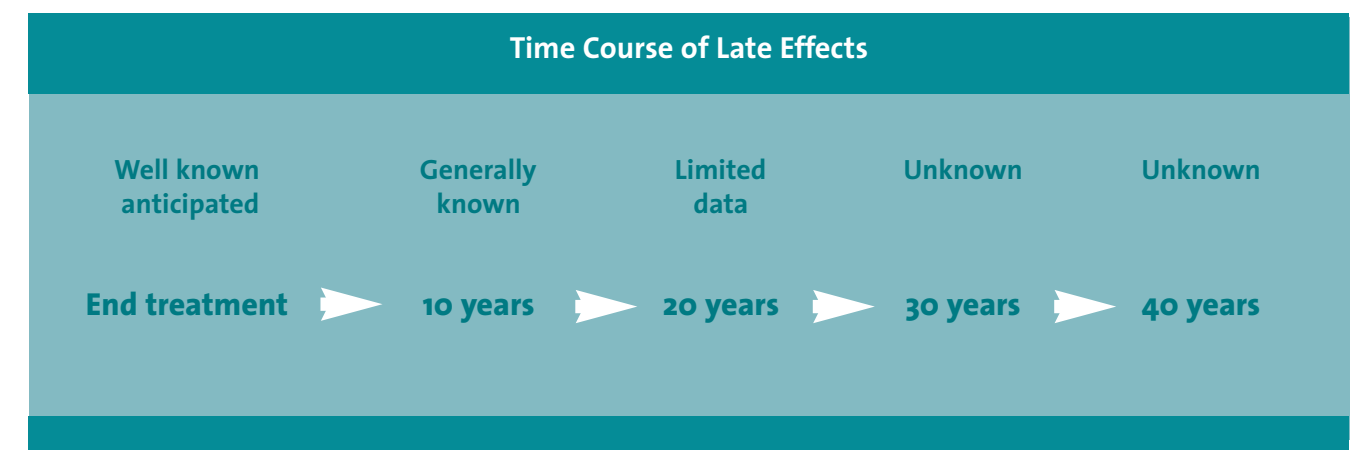
While the re-occurrence or 'relapse' of the original disease – cancer that may not have been completely eliminated during the initial treatment - has traditionally been the greatest fear of cancer patients and their families, the late effects of cancer and its treatment have increasingly become the focus of concern for both families and medical practitioners. These effects include:

- Medical effects
- Neuropsychological effects
- Psychosocial effects
- Educational/vocational effects

LATE EFFECTS ARE AN EVOLVING PICTURE

Today's treatments are the authors of tomorrow's late effects. Oncologists can reasonably predict late effects up to 10 years after the end of treatment.

However, less is known about the effects 20 years after treatment, and very little data exists for survivors who are 30 or 40 years post treatment.



About survival rates

Just as there are various types of cancer, so are there different treatment methods and survival rates. For example:

- **Acute Lymphoblastic Leukemia (ALL):** is the most common childhood cancer, with a survival rate approaching 84 percent (POGONIS, 2012).
- **Hodgkin's Disease:** five-year survival rates are at 94 percent (POGONIS, 2012)
- **Germ-cell tumours:** five-year survival rates are at 89 percent (POGONIS, 2012).
- **Medulloblastoma:** five-year survival rates for tumours without spread are approximately 80 percent (Packer, 2006).

Insight

While generalized predictions can be made about this population, individual outcomes are always unique and warrant careful assessment prior to intervention.

MEDICAL EFFECTS

The medical late effects of childhood cancer may result from the disease itself and from the effects of therapies such as radiation and chemotherapy. For survivors, these effects may impact:

- **Brain function:** which in turn can lead to learning deficits

Physical growth: which may be slower during treatment, and may in some circumstances be limited or altered permanently

Reproductive function: both with respect to reduced sperm production in males and altered ovarian function in females which may in some cases lead to reproductive problems

Sensory impairments: which may affect eyesight or hearing

Heart function: which may lead to

heart conditions that may be progressive over time, or have their onset later in life.

“SAVTI is willing to take the time to sit and talk with us about any questions, comments or concerns about high school, post-secondary education or work experience that we may have.”

NEUROPSYCHOLOGICAL EFFECTS

Many survivors of childhood cancer will have experienced neurocognitive changes that affect thinking, learning, memory, attention and infor-

mation processing. For cancer survivors, these are frequently more limiting to overall quality of life than physical or medical problems.

In the population of childhood cancer survivors who are approaching the time for post-secondary education, approximately 20 to 25 percent will experience some degree of neurocognitive dysfunction.

Information processing: many survivors have a slower rate of information processing. These young people may be slower to understand concepts, read more slowly, take longer to complete their work, and therefore may require a longer allotted time period to finish tests and exams.

Distractibility: cancer survivors may also exhibit signs of inattention and distractibility. In a classroom setting, for example, the speed and amount of information being transmitted may easily overwhelm the student who, as a result, will 'tune out'. At home, distractions such as a television program or telephone conversation in the background may hamper a student's ability to focus on his or her homework.

Learning and memory: cancer survivors may have difficulty with rote learning – math or history facts, for example, or sequences such as a shopping list.

They may also experience fast forgetting – students may study hard for an exam, but find that they 'go blank' during the test itself. They may know how to spell a particular word one week, but not the next. They may also forget to pass on messages – from school to home, for example – and they may frequently forget to bring home textbooks or personal belongings.

In addition, they may experience a decrease in what is referred to as 'working memory' – the ability to process multiple channels of information at one time or mentally manipulate information.

Cancer survivors experiencing these deficits might, for example, have difficulty taking notes in a classroom while listening to the lecture at the same time. These cancer survivors:

- Work on only one channel at a time
- Can't manage multiple demands
- Can't cope with interruptions.

Organizational challenges: cancer survivors may have difficulty with planning and organization, or prioritizing multiple assignments. This may include:

- Having difficulty deciding where to start on a large task
- Having trouble keeping track of progress through a complex project
- Having difficulty keeping track of assignments and homework, and physically organizing materials.

PSYCHOSOCIAL EFFECTS

Despite the overwhelming challenges childhood cancer survivors face, many studies indicate that most of these young adult survivors go on to function normally without any significant emotional problems. However, some survivors and their families do experience more significant adjustment and emotional issues.

Family stress: while many survivors and families report they have grown closer and wiser as a result of their child's illness, others indicate there may be negative effects. Fear of the unknown and loss of confidence in the future can lead parents to anxious and protective behaviours which, if extreme, can hinder the development of independent, confident behaviour in the survivor – and sometimes in their siblings as well. Where parents must leave work to care for an ill child, financial burdens can further intensify family stress.

Emotional challenges: survivors of childhood cancer may face a variety of challenges including low self-esteem, depression, preoccupation with their physical condition and a negative body image.

Post-traumatic stress disorder (PTSD): considering the potentially traumatic nature of the cancer experience, it is not surprising that both patients and parents sometimes exhibit symptoms of post-traumatic stress disorder. The treatment itself, which includes many painful and invasive procedures, frequent hospitalizations and separations from family and friends, can be a frightening and isolating experience.

EDUCATIONAL/ VOCATIONAL EFFECTS

As a result of neurocognitive deficits, many survivors of childhood cancer face a variety of learning challenges in the educational setting which also impact later vocational choices and opportunities. In the absence of adequate support, these and other challenges can adversely affect their success in later life, and prevent them from realizing their full potential.

Social and academic development: many months, even years, of treatment can result in lost education time, impacting both academic and social development.

Educational attainment: a tendency not to pursue higher education has been reported among some sub-groups of survivors who do not have the necessary support.

Employment and financial stability: survivors may also often have more difficulties finding employment, acquiring health and life insurance and obtaining loans.

In their own voices: The Many Faces of Survivorship

I CAN DO THIS

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

A pervasive theme throughout the SAVTI research interviews was the high level of determination among cancer survivors. When faced with the suggestion that they lower their expectations, these young adults expressed a strong will to 'show them'

"I had the doctors tell me that I would never graduate high school. They said that I would never ride a bike. I can't ride a bike yet but I graduated from high school. When I went into high school I had that in my head and as I graduated into each grade, I was like yeah, well I'm showing you."

and prove them wrong. Like their peers, achievements and successes propelled survivors into feeling more confident and determined to reach their next objectives.

Almost all of the survivors interviewed had specific career goals and plans for their achievement, including becoming a chef, horticulturalist, engineer, mechanic, broadcaster, industrial designer and teacher. However, pursuit of their dreams

is often hampered by inertia – an inability to follow through on plans and goals. Although we do not yet understand the source of this problem, psychologists, educators and counsellors report that, as a result, some of these young people have great difficulty with sustained effort.

"He has a dream of becoming a police officer. He has a dream of going there but I know it is not possible. I'm thinking if I tell him that you can't be - maybe he will stop going to school or something."

Parent

Parents of a group of survivors, interviewed by SAVTI, expressed fear that their children's dreams were unrealistic. They worried that such expectations would lead to further disappointments and discouragement – which sometimes occurs. Without direction and support, parents felt ill-equipped to advise their children.

Perhaps, because of the difficulties these young survivors have faced, they often possess an underlying courage and determination. For many with neurocognitive challenges, however, the ability to follow through on plans and goals may impede progress, despite these positive attitudes. Thus, the courage and determination of cancer survivors must be channelled toward the adoption and achievement of realistic goals.

Juan

JUAN WAS DIAGNOSED with a medulloblastoma (malignant brain tumour) at age 8, treated with surgery, radiation to the whole brain and spine, and chemotherapy. He was in grade 3 at the time of his diagnosis and missed most of that school year.

Prior to diagnosis, he was considered an average student and had no difficulties at school or with friends. When he returned to school in grade 4, he was immediately challenged by the curriculum and it was difficult for him to keep up in the playground. An initial neuropsychological assessment was conducted during his grade 4 year, and identified average intellectual abilities. However, his academic skills were below grade expectations, and this was particularly evident in his basic math skills. He was also slower than other children his age in terms of motor speed, fine motor dexterity, and gross motor coordination.

As a result, he had a hard time copying from the blackboard in school and finishing work in the allotted time. His hand would get tired when he was writing, and his written work was therefore short and did not include much detail. He was also having trouble outside the classroom. For example, he was no longer able to play soccer with his friends at recess and tended to spend his time with the teachers. The neuropsychologist presented her findings at an Identification, Placement and Review Process (IPRC), along with recommendations for identification and modifications and accommodations to the curriculum.

By Grade 10, Juan was experiencing physical challenges. He was short of stature, had delayed onset of puberty, and thin hair, which made him look considerably different from his peers. As well, his neuropsychological deficits had worsened. His IQ had declined relative to his earlier assessment and the problems identified previously were more prominent. It was harder for him to cope with the demands of the high school curriculum, particularly because of the lack of support

and structure – he was now expected to schedule, organize, and plan his own projects as well as work on teams with other students. Problems with inertia, speed, and cognitive abilities interfered with his successes in high school. Increasing recognition of his differences and his struggles took its toll on his mood and self esteem. He became increasingly withdrawn and socially isolated.

Juan was referred to SAVTI while in Grade 11. Through a series of appointments, the SAVTI co-ordinator worked with Juan to determine the appropriate steps that should be taken toward high school completion and beyond. As school was difficult, the subjects Juan took in Grade 11 and Grade 12 were essentials level courses. He also did two co-ops. The SAVTI co-ordinator arranged with the co-op teacher to have Juan complete his second co-op placement at a business where Juan felt he could manage and at which he was moderately successful. Through the Individual Education Plan (IEP) developed for Juan at his school, he was better able to handle the work in the classroom.

The plan for Juan was to have him complete Grade 12 with an Ontario Secondary School Certificate and then to apply to a vocational program at a college. The one-year college program would allow Juan to attend a placement at two different work locations, gaining further skills that would better prepare him for the workforce. As well, by participating in the communication and life skills training offered in the program, he would be able to practice becoming more effective in communicating and interacting with others in a supportive environment.

Now in his second semester of the vocational program, Juan is attending his second placement and feels better able to cope in the workplace. He will keep in touch with the SAVTI co-ordinator to ensure that the next transition – to employment – goes smoothly.



The Impact for Survivors: 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.

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.

Combined with the health issues and potential late-effects of treatment, some young cancer survivors must cope with, the maturational process can be particularly problematic.

THE CHALLENGE OF TRANSITION

Survivors of childhood cancer must, in late adolescence and early adulthood, 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

Survivors Face Multiple Transitions		
Developmental Transition		
Child	➡	Adult
Health Care Transition		
Pediatric Hospital	➡	Adult Hospital
Educational Transition		
High School	➡	Post Secondary

necessarily be good strategies now. These new challenges may mean that some young adults who have coped successfully in the past – those with milder effects, for example, now cope less effectively. For others, late effects may be more complex in 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 to these individuals.

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.

“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.”



Photographer: Leigh Tynan

The transition from child to adult usually begins at approximately age 12, and continues into the late 20s. For cancer survivors, this process may take longer and include added delays.

A number of additional issues may emerge:

Body image: the survivor's body image may present challenges to creating an identity – being 'different' is an unwelcome barrier at this age.

Parental protectiveness: deeply engrained over many years of third-party decision making in the health care context, 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 survivors have additional challenges establishing a circle of relationships outside the family.

Dependency: illness itself creates physical dependency on parents which may impact the young person's ability to develop autonomy, or desire for 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 survivors during this transition include the following:

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

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

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

Insight

Some survivors of childhood cancer may have limited knowledge of their own medical history.

In a study of young adults 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 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. C*

Medical care: annual visits to a follow-up (AfterCare) clinic system for adult survivors are important to ensure that survivors receive the kind of medical care they need to minimize their late effects.

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

EDUCATIONAL/VOCATIONAL TRANSITION

Educational/vocational transition means:

- Succeeding in more independent study
- Having fewer opportunities for feedback

Implications in the workplace include:

- 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

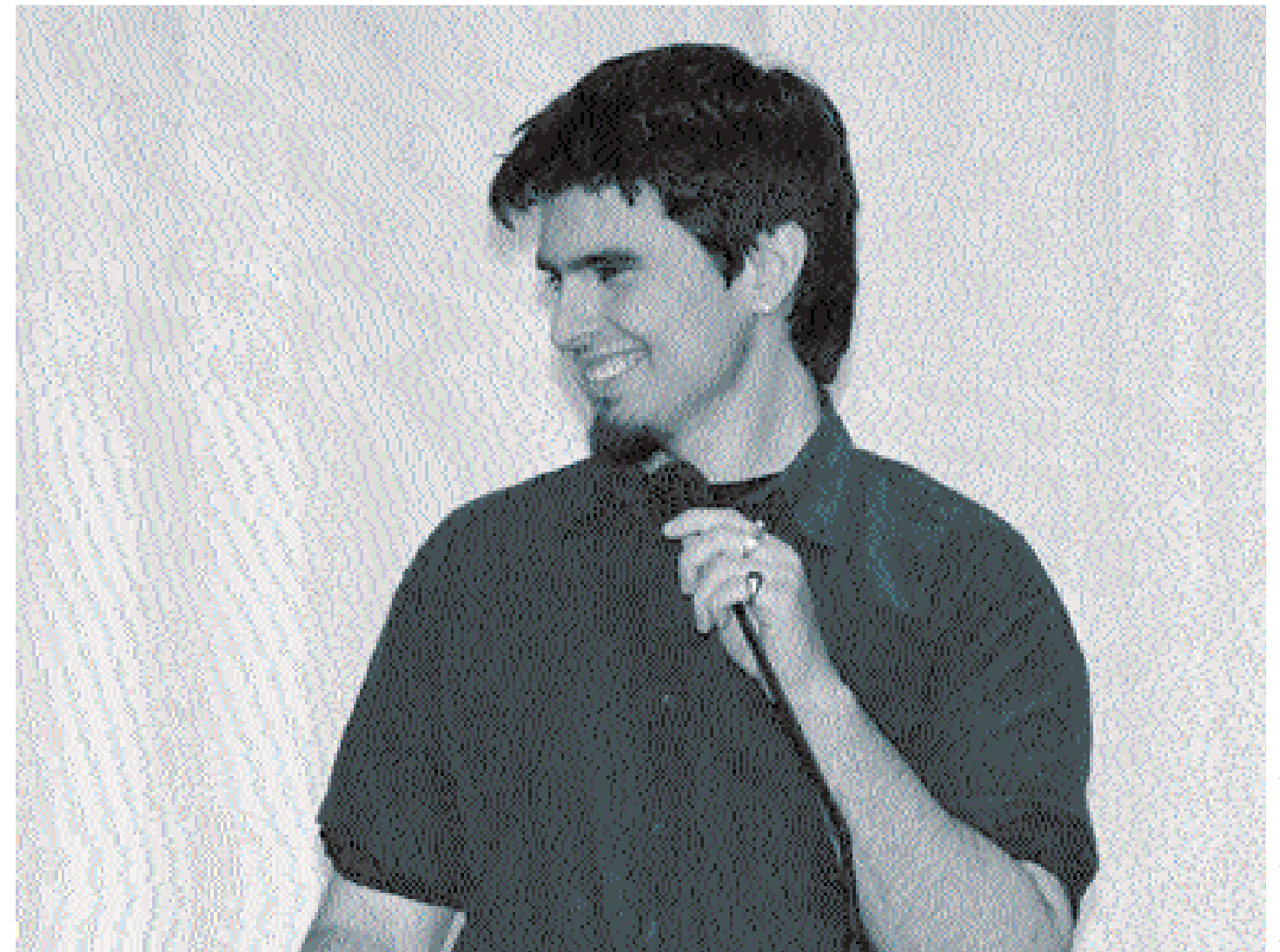
Implications in the post-secondary setting include:

- 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 for young cancer survivors to assume personal responsibility, make appropriate self-disclosure of health issues, advocate on their 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 young survivors' success in making the transition to post-secondary education and, ultimately, the workplace.

Cognitive deficits: for childhood cancer survivors with cognitive deficits, the transition from high school to post-secondary education or employment may be particularly challenging. These young people must negotiate impairments of attention processing, memory and, in some cases, motor skills, at the same time as they deal with the new challenges of higher education or employment. Research has shown that the cancer survivor's intellectual capacity on completion of treatment is the most accurate predictor of his or her successful integration into society. It is therefore crucial that expert advice be sought to ensure that these individuals are placed on an appropriate educational and career trajectory, and that required supports are both identified and available.



Photographer: Irv Kochman

Expectations for achievement: low expectations of survivors can undermine their efforts to attend school or look for a job. Likewise, unrealistic expectations, on the part of the cancer survivor or the counsellor, can result in frustration and discouragement. It is important that plans and goals be aligned with the survivor's capabilities, and that they neither underestimate nor overestimate what each individual may be capable of achieving.

Motivation: the degree of motivation experienced by the survivor is another significant factor in achieving this transition. Some childhood cancer survivors seem to be satisfied with survival and are not motivated to pursue future aspirations. Others may be motivated to exceed expectations of their future

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 young adults successfully negotiate developmental, health care, and educational/vocational transitions as a critical step toward future success across all the dimensions of adulthood.

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.

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

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

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

main motives expressed for returning to school was to get to know more people. Yet for many cancer survivors, their social life was limited.



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 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.

"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

Jasmina

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 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.

4 Pathways to Success: What We Can Do

Successful academic and vocational transitions are a critical issue for survivors of childhood cancer and 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 potential late effects of cancer and its treatment, and their implications for transitioning into adulthood, is a critical first step toward supporting survivors of childhood cancer. SAVTI strongly recommends that counsellors working with these young adults, however, integrate specialized knowledge into the counselling process itself.

When working with survivors of childhood cancer, qualified counsellors should have a sound knowledge of the individual survivor's medical history and current profile, including late effects.

The critical challenge lies in the connection of this essential medical information, and the individual survivor's goals, dreams, aspirations and aptitudes, to arrive at appropriate and individualized educational and vocational goals and plans to achieve them.

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

LATE EFFECTS PRESENT A COMPLEX PICTURE

There is often considerable complexity involved in assessing the interaction among late effects, medical and personal history, career and life goals, and the educational and vocational opportunities available.

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 – 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 population of young adults.

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 previous illness and treatment history. Like all young adults, survivors may also be unclear about the requirements and demands of a profession that appeals to them.

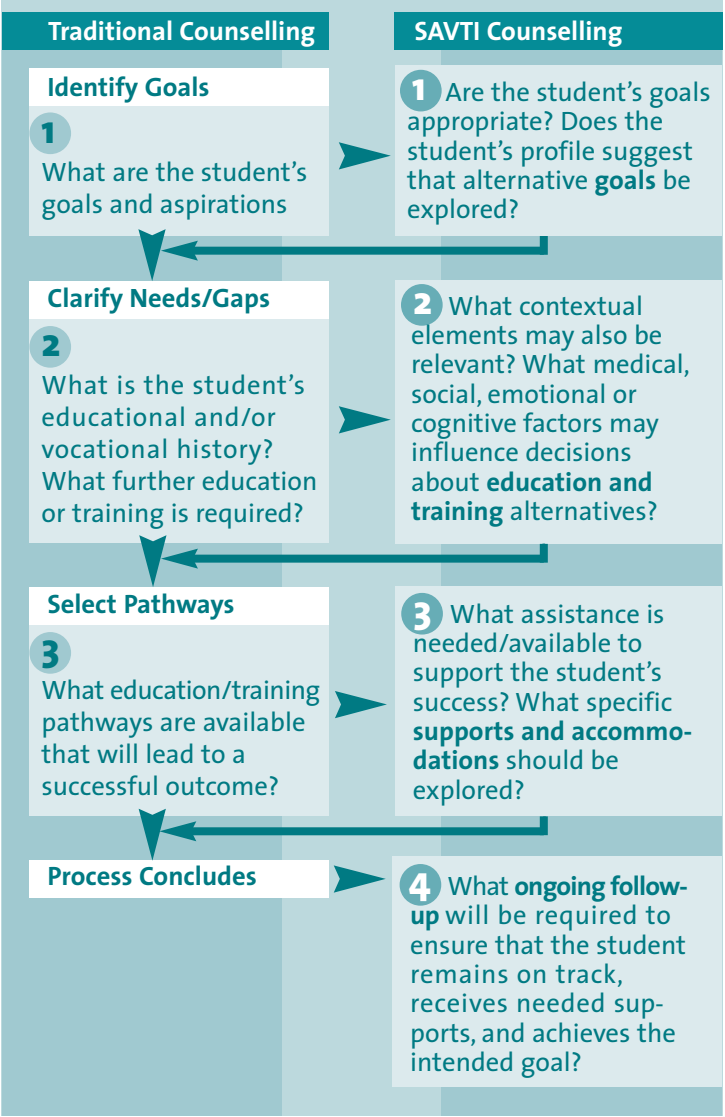
Here, the consequences of making an unrealistic educational or career choice can be significant, undermining the individual's ability to succeed, and potentially leading to failure and considerable reluctance to try again in a more appropriate setting.

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, for example, 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.

Generally, young adults with neurocognitive late effects will have had 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 late effects, and their implications for both the educational setting and the workplace. It is important to stress, however, that survivors 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 Hearing impairment 	<ul style="list-style-type: none"> Student may require supports such as enlarged text, brailled text, specialized computer equipment Student may benefit from an in-class note taker Student may benefit from audio support to ensure that the instructor is heard clearly Student may need extra time to write tests/exams Student may need voice activated software 	<ul style="list-style-type: none"> May not be suited to occupations in which sensory abilities are critical (pilot) Safety issues arising from visual/hearing impairment should be considered The employee needs to take responsibility for advising the employer or supervisor of the best ways to ensure effective communication
Motor <ul style="list-style-type: none"> Paralysis/weakness Gait/balance issues 	<ul style="list-style-type: none"> Issues in the classroom are minimal in some cases, although deficits in fine motor skills may interfere with handwriting and note-taking ability Travel distances between classes on a large campus may be considered Extra time may be needed for tests/exams Issues may arise where students participate in co-op placements (see Appendix for information) Student may require frequent breaks 	<ul style="list-style-type: none"> Individual's motor skills must be matched to job requirements Particularly where safety is an issue, the individual must self-identify to the employer
Physical Exertion <ul style="list-style-type: none"> Fatigue Easily tired 	<ul style="list-style-type: none"> Scheduling may be planned to avoid large continuous blocks of class time and/or classes toward the end of the day, depending on the needs of the individual student (it is important to ask the student when, and under what circumstances he or she experiences fatigue) Student may require reduced course load 	<ul style="list-style-type: none"> Individual may require frequent breaks Shift work should be avoided in favour of regularly scheduled work Work with frequent deadlines and pressures may not be advisable

Challenges	Implications at school...	Implications at work...
Medical <ul style="list-style-type: none"> Medical conditions Required treatment Required medication 	<ul style="list-style-type: none"> Medications may interfere with learning and attention Mental health issues may interfere with schooling Medical appointments and/or absences may require accommodation 	<ul style="list-style-type: none"> Individual may require time off work for appointments and/or absences Effect of medications should be explored with respect to both job requirements and safety issues
Attention <ul style="list-style-type: none"> Distractibility Sensitivity to information overload Difficulty with multi-tasking 	<ul style="list-style-type: none"> Accommodations such as sitting at the front of class, having notes in advance, having a note-taker will help the student focus on instructional content Instructions should be clear and explicit Assistance may be needed to break information down into short, digestible pieces 	<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 (commercial kitchen) Clear instructions and one-task-at-a-time are preferred work modes The employee must take responsibility to explain to the supervisor the most effective way to receive instructions, rather than hoping the supervisor will 'figure it out'
Working Memory <ul style="list-style-type: none"> Short-term memory deficits Difficulty with simultaneous retention or processing of multiple ideas/information 	<ul style="list-style-type: none"> Accommodations such as sitting at the front of class, having notes in advance, having a note-taker will help the student focus on instructional content Instructions should be clear and explicit Student will need to develop the habit of consistently writing things down Student may need a fact sheet 	<ul style="list-style-type: none"> Written instructions are highly preferred over verbal instructions The employee will need to develop the habit of consistently writing instructions/information down for later recall Occupations requiring rapid-fire multiple information inputs or instructions may be inadvisable (taxi dispatcher, air traffic controller)
Processing Speed <ul style="list-style-type: none"> Longer time required to process information Delay between question and response (verbal or written) Difficulty with high rate of information input 	<ul style="list-style-type: none"> Student may need to self-identify so that instructors and peers are aware and can accommodate Accommodations such as longer test times or extended time for writing/essays may be required A note taker, tape recording or similar may assist the student in reviewing content at his/her own pace 	<ul style="list-style-type: none"> Individual may want to avoid occupations in which rapid response is a critical job skill (customer service representative) The occupation should match the individual's ability to receive/process and respond to information

Challenges	Implications at school...	Implications at work...
Memory and Learning <ul style="list-style-type: none"> Slow rate of new learning Fast forgetting Difficulty with rote learning 	<ul style="list-style-type: none"> Rote learning (out of context) will require particular effort and support Accommodations such as the use of notes during exams may be required for students who experience difficulty with recall Recognition format tests may be more appropriate than fill-in-the-blanks Student should develop the habit of writing things down or using a digital recorder as a memory aid Student may need to use an electronic organizer/daytimer Student may require an individualized timetable 	<ul style="list-style-type: none"> Occupations which require a high rate of continuous new learning/new information may be challenging The employee will need to develop the habit of consistently writing instructions/information down for later recall When engaging in a training program, the employee may wish to request any required accommodations
Inertia <ul style="list-style-type: none"> Difficulty with 'follow-through' Although motivated to pursue a goal/outcome, the individual may have difficulty consistently taking action A separation between 'intent' and 'action' 	<ul style="list-style-type: none"> Student will need good time management/project management skills, supported by aids such as a daytimer. In many cases, these skills will be in development, and support will be needed for success Very often, a peer or other supportive individual may be enlisted to help the student stay on track Key assignments such as homework/essays must be diligently recorded by the student Particular attention must be paid to managing deadlines Student may need large assignments broken into smaller tasks 	<ul style="list-style-type: none"> Failure to follow through on plans/schedules may cause serious employability issues if not addressed Employees will need to develop exceptional time management/project management skills through the use of aids such as paper or electronic schedulers Individuals may wish to pursue occupations in which incoming workflow determines their actions, rather than adherence to a long-term plan
Mood <ul style="list-style-type: none"> Depression Anxiety 	<ul style="list-style-type: none"> Depression or anxiety may result in missed attendance, missed assignments Student may require counselling support 	<ul style="list-style-type: none"> Depression and anxiety can adversely affect work performance and interpersonal relationships on the job Employees may require counselling support

Challenges	Implications at school...	Implications at work...
Autonomy <ul style="list-style-type: none"> Over-reliance on parents Slower transition to full adult autonomy Hesitation over decision-making 	<ul style="list-style-type: none"> Guidance counsellors and others in the college/university setting work with students as adults. Students need opportunities to develop a sense of mastery, independent of parental support Student may need explicit support in developing decision-making skills and confidence in using those skills Student may need encouragement and support to develop self-management and advocacy skills It may be necessary to work directly with parents to help redefine parent-child relationships and support encouragement of autonomy 	<ul style="list-style-type: none"> Occupations which focus on carrying out established processes (purchasing agent) may be preferred over those emphasising decision-making (project planner) It is important to keep in mind, however, 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 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
Identity <ul style="list-style-type: none"> Self-esteem Anxiety about 'differentness' Physical issues 	<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 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 Student may require counselling support, with particular focus on fostering social acceptance from peers Student may require mentors 	<ul style="list-style-type: none"> Employees with low self-esteem may encounter social issues at work Anxiety may also diminish an employee's overall sense of confidence Employees may require counselling support and identification of specific strategies to reduce anxiety and build confidence Team-building exercises may also be of benefit
High-Risk Behaviour <ul style="list-style-type: none"> Drug use Drinking Smoking Unprotected sex/Inappropriate sexual behaviours 	<ul style="list-style-type: none"> Students' interest in the development of a social circle may lead to behaviours which have unique complications for childhood cancer survivors 	<ul style="list-style-type: none"> Inappropriate social/sexual behaviours in the workplace may have serious legal and employment consequences

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 history, and the implications of illness and late effects for future learning.

For example, a student survivor may have achieved successful results in secondary school, but 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.

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 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 pathways, additional services and accommodations may need to be considered for survivors of childhood cancer.

The effects of childhood cancer treatment may result in an 'inertia' exhibited by some cancer survivors. 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. As a result, an effective counselling process for this population must not only identify an appropriate educational 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.

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.

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 T: 519-685-8500 ext.52527

Hamilton T: 416-592-1232 ext.244

Ottawa & Kingston T: 613-737-7600 ext. 3495

Toronto T: 416-592-1232 ext. 255 & 244

Toll free #: 1-855-367-7646

See the concluding chapter of this guide for a detailed description of the SAVTI program and POGO which plans and coordinates cancer control in the province of Ontario.

Insight

Transitioning into post-secondary education

For many survivors of childhood cancer, college and university programs will not represent a challenge. These students, who have done well in their high school studies, will 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, for example, 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 achieve to an appropriate level. It is important to keep in mind that each institution will have its own distinct procedures in place 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, students who had not received accommodation in the elementary/secondary sys-

tem were in some cases 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. In this case, there is some risk that the student may not feel he or she needs accommodation in the post-secondary setting.

In either case, care must be taken to assess the student's ability to do post-secondary work, and the availability of necessary supports to help the student achieve his or her academic potential. Students who embark on a program of study not commensurate with their abilities not only risk failure and withdrawal from the program, but the added burden of discouragement which may prevent them from trying again in the future.

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 facilities that may be present.

Social preferences: some students may enjoy the benefits of a small college or university campus where they can 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 optimum 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 basis and provide more personalized 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

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 co-ordinator would assist him with the application process and would ensure that he link with the Disability Services in the college, once he is accepted.

Building Successful Futures: SAVTI and POGO

The Successful Academic and Vocational Transition Initiative (SAVTI) is a program of Pediatric Oncology Group of Ontario (POGO) designed to ensure that survivors of childhood cancer receive the counselling and other supports they need to transition into adult life and achieve their potential.

ABOUT SAVTI

The Successful Academic and Vocational Transition Initiative develops information materials and educational programs for service providers across Ontario and provides direct counselling support to survivors of childhood cancer.

SAVTI's professional learning programs are designed to meet the needs of professionals in health care, educational, and vocational counselling settings for sound information to guide the counselling process and ensure that childhood cancer survivors are supported as they transition into the worlds of work and adult life. SAVTI programs also aim to open the way to knowledge exchange among different sectors.

SUPPORTING CRITICAL TRANSITIONS

SAVTI programs are focused in particular on helping childhood cancer survivors with neurocognitive challenges transition into positive educational and vocational destinations, while taking into account the need to navigate transitions such as:

- Transition through high school to post-secondary education or training
- Transition into careers and the workplace
- Transition from the pediatric to general health care setting
- Transition from adolescence to adulthood
- Transition from third-party decision-making to self-directed decision-making

DEVELOPING A CLIENT SERVICE MODEL

SAVTI provides counselling services to childhood cancer survivors through referrals from AfterCare clinics across the province. While the ultimate intent of the SAVTI initiative is the transfer of knowledge to counselling professionals, these direct SAVTI counselling services are designed to bridge a current knowledge gap, and provide a means to continuously improve our counselling model.

SAVTI's counselling process is uniquely tailored to the needs of childhood cancer survivors. SAVTI helps young adults to:

- Identify appropriate career options and goals
- Develop a personal education or employment plan
- Prepare for admission to a college or university or the workplace
- Engage strategies for success in school and at work
- Link with appropriate services and supports within the educational system and the community
- Connect with a buddy or mentor
- Develop self-advocacy skills
- Experience knowledgeable and sensitive support while achieving life and career goals.

BUILDING A SHARED KNOWLEDGE BASE

SAVTI is committed to developing and sharing best practices for childhood cancer survivors and building vital links with and between educational, vocational and community organizations.

SAVTI is pursuing the expansion of partnerships across the spectrum of education and training organizations including apprenticeship, colleges, universities, schools and school boards, and community agencies.

Resources

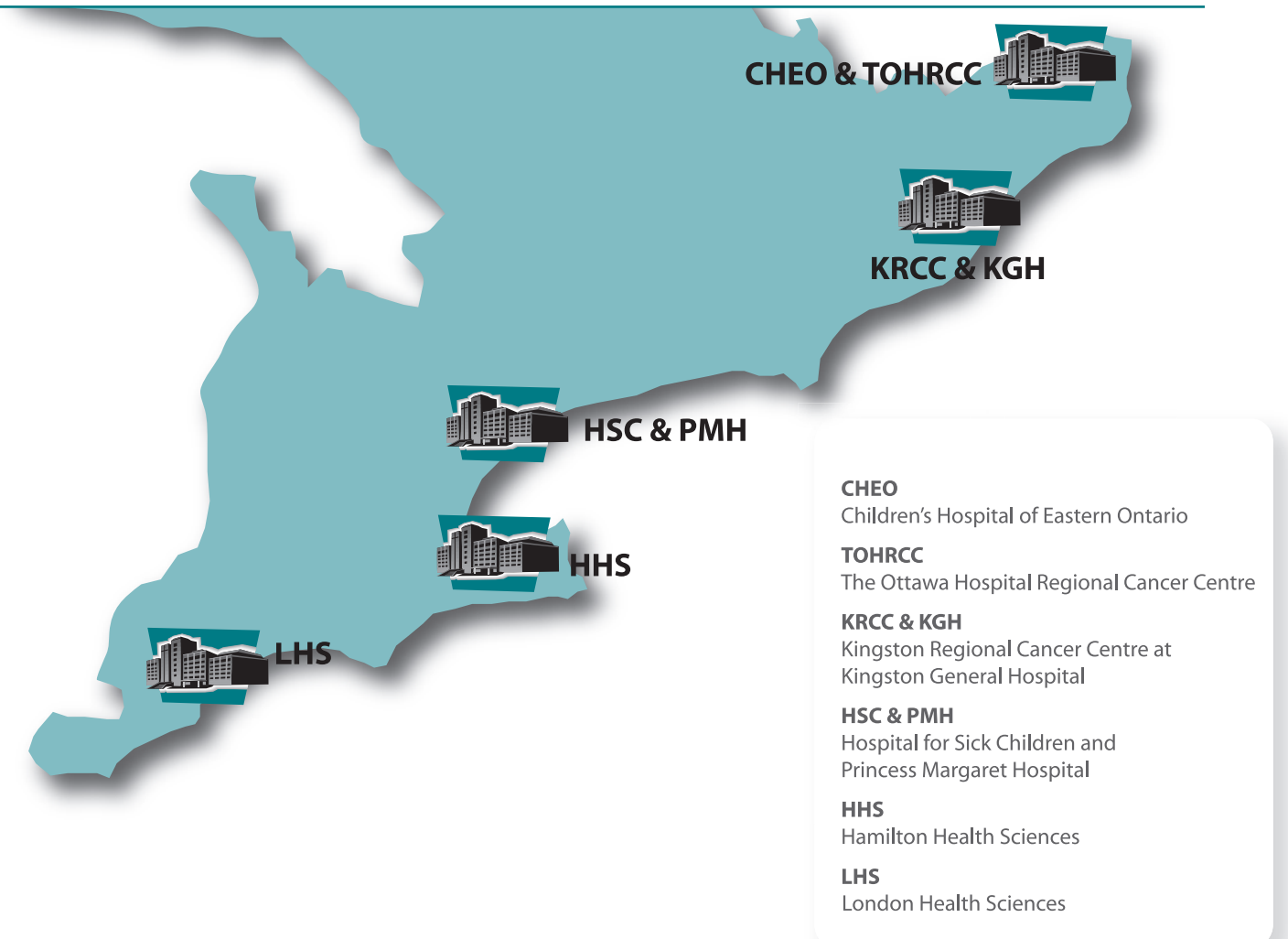
Visit our website at www.pogo.ca/care/savti/ to learn more about tools and resources for childhood cancer survivors and their families.

SAVTI: Goals and Outcomes

By integrating the expertise drawn from the health care, education and vocational counselling fields SAVTI will:

- Identify education and employment barriers for youth
- Identify and facilitate appropriate education and employment pathways
- Develop the necessary system-wide and client-specific strategies to successfully achieve educational and vocational objectives and create expanded opportunities for young adults that may include apprenticeship or the workplace
- Provide ongoing support as the individual cancer survivor seeks to realize independence
- Advance the educational, vocational, social and personal quality of life for survivors of childhood cancer, and enhance self-esteem and wellness
- Codify and transfer knowledge about transition support for medically fragile adolescents and young adults

SAVTI: Referral sources, POGO AfterCare clinics in Ontario



These partnerships, in turn, will contribute expertise, best practices, information and resources, and serve as a conduit for knowledge exchange.

ABOUT POGO

The SAVTI program is an initiative of Pediatric Oncology Group of Ontario. POGO provides the SAVTI team with access to its provincial AfterCare network and its extensive expertise, health care materials, and resources.

A PROVINCE-WIDE PARTNERSHIP

POGO is the advisor to the provincial government on childhood cancer control – an Ontario-wide consortium created in 1983 by a group of childhood cancer experts who recognized the need for an integrated networked system of care for children with cancer.

POGO's principal and founding partners are the pediatric oncology units in five academic health science centre-affiliated children's hospitals in Ontario. Today its partners include community hospitals, community organizations, parents of children with cancer, and survivors of childhood cancer.

IDENTIFYING CRITICAL SERVICE GAPS

Since its inception, POGO has evolved into a multi-disciplinary organization focused on identifying critical gaps and needs across the spectrum of cancer control in childhood and adolescence. (See diagram on next page.) Today, POGO:

- Plans, coordinates, develops and implements childhood cancer services for Ontario
- Facilitates access to service for childhood cancer patients and their families

- Provides professional education regarding care of the child with cancer and survivors of malignant disease
- Advises the Ministry of Health and Long-Term Care on childhood cancer control
- Provides financial assistance to families with children undergoing treatment.

POGO AND THE EVOLUTION OF SAVTI

POGO health care professionals recognized that many survivors are experiencing academic and vocational difficulties during their transition from adolescence to adulthood.

To address that issue, POGO initiated a collaboration with George Brown College, creating an intervention program to facilitate the transition of these survivors with late effects, from high school to post-secondary education, and beyond to employment and independent living.

SAVTI is an established program of the Pediatric Oncology Group of Ontario, with local service in Ottawa, Kingston, Hamilton, London and the Greater Toronto Area (GTA).

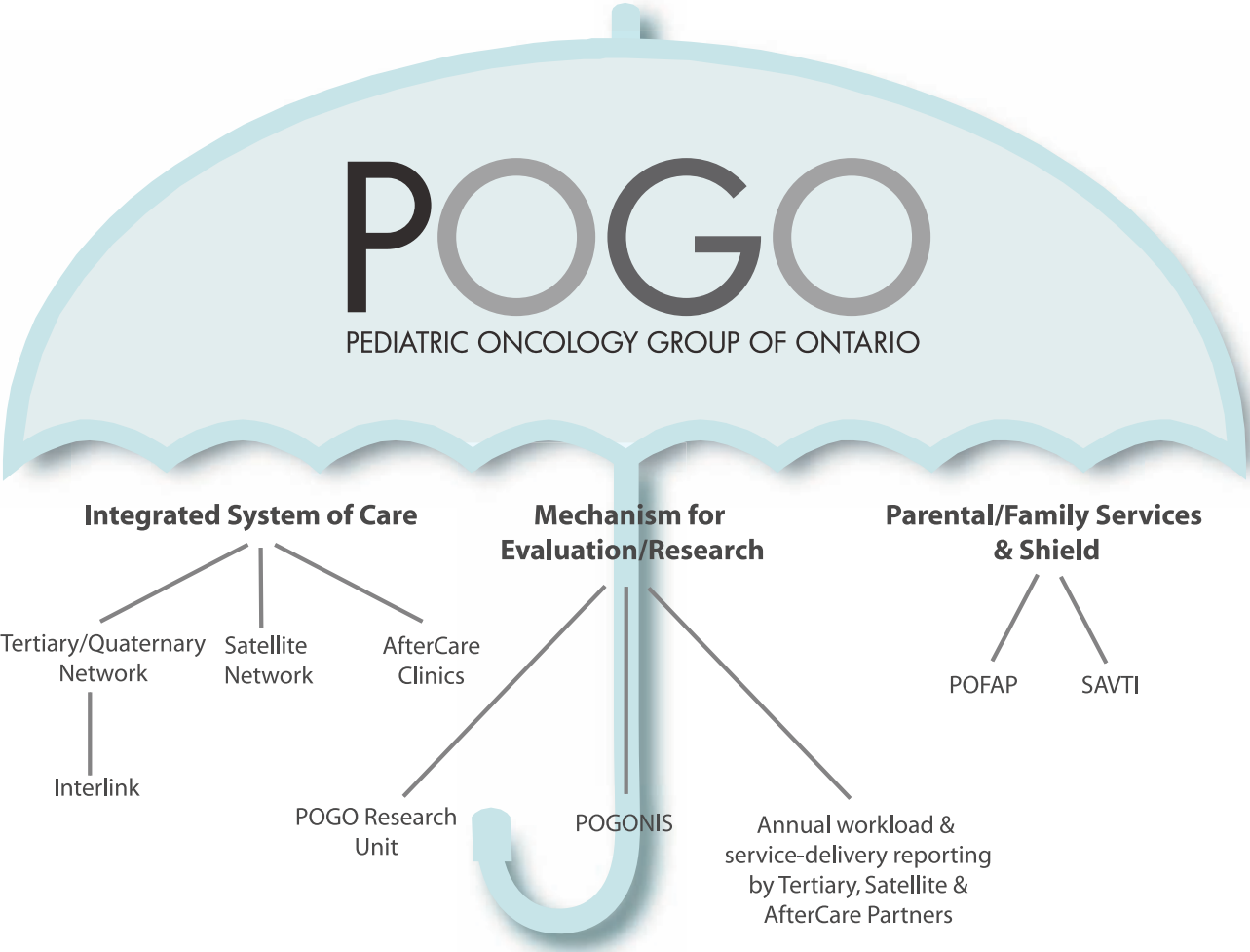
For contact information for SAVTI counsellors, go to the POGO website: www.pogo.ca/care/savti/

WE INVITE YOUR COMMENTS AND QUESTIONS

If you have comments or suggestions about this guide, or other SAVTI programs and services, contact us at savti@pogo.ca or write to:

SAVTI Provincial Coordinator
Pediatric Oncology Group of Ontario
480 University Avenue, Suite 1014
Toronto Ontario M5G 1V2 , Canada.

We welcome your response.



You can keep up to date on new programs, services and information resources by visiting the SAVTI and POGO websites at:
SAVTI: www.pogo.ca/savti/
POGO: www.pogo.ca

In their own voices:
The Many Faces of Survivorship

I HAVE GOALS AND DREAMS

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

Cancer survivor narratives describe a group of young people who are extremely determined, motivated, and dedicated, with clear aspirations for the future.

"I found out about all the universities and then I went to SAVTI and it was kind of a little bit of relief that I could get help and that I wasn't on my own like the other kids were."

Survivors interviewed provided insights into challenges they faced, such as minimal expectations on the part of medical service providers and teachers, the frustration and challenges of daily life at home and in school.

Family members interviewed wanted to see them achieve the highest degree of independence possible and to have a future that included meaningful work.

The survivors of childhood cancer in this study typically focused on having a place in the world, independence, a meaningful relationship, marriage, and children. And most were aware of the steps they needed to take in order to reach these goals.

The discrepancy between the minimal expectations of service providers and those of survivors and their families, underscores the importance of providing these young people with the supports and counselling they need to achieve their highest potential.

"I want to do post secondary education. I want to go to college. I want to get a good job, like support myself. I want to start a family, get married... whatever. I would like to be on my own. I would like to know that I could do that."



Stacey

STACEY WAS DIAGNOSED with Acute Lymphoblastic Leukemia (ALL) when she was six years old. She received cranial radiation and chemotherapy. In high school, Stacey had difficulty with some subjects. She had an Individual Education Plan (IEP), which allowed for extra time on tests and a calculator for math. She had to work hard on assignments and worked long hours.

Her first contact with SAVTI was at age 17, when she was in grade 11. She had been referred to SAVTI because she needed guidance on appropriate education and career choices. Initially, the SAVTI coordinator exchanged emails with Stacey and her mother, and recommended websites they could visit to learn about a variety of careers. Following this exploration, they met to discuss plans for college.

After the meeting, college literature and information on a number of options were sent to Stacey. Two years later, Stacey contacted SAVTI again because she had decided to apply to university, rather than college programs. The SAVTI coordinator explained SAVTI's role in ensuring that she is connected with counselling services for any accommodations she might need. The coordinator also explained that, if and when she received acceptance offers from universities, she could ask SAVTI for help in making the appropriate choice.

Some months later, SAVTI was contacted by Stacey's mother, who explained that Stacey had not indicated any disabilities on her university application, was at risk of not being accepted, and felt frustrated and lost. The SAVTI co-ordinator identified a number of colleges that offer a one-year program to facilitate transition into university. One month later, Stacey was successfully accepted into college.

Abe

ABE WAS DIAGNOSED with a brain tumour at age five and received cranial radiation. He completed high school with an IEP. It was a struggle for Abe to get his diploma and he had to stay an extra two years to finish.

Abe contacted SAVTI at the age of 22, while he was in college. He was struggling in school and not receiving the help he needed. He was worried about failing and unsure about how to choose a future direction that might lead to meaningful employment.

The SAVTI coordinator identified a means to recover some of Abe's lost credits, while at the same time exploring a variety of career options. While researching the field in which Abe was studying, the coordinator discovered that, as an alternative to college, there were opportunities to receive on-the-job training.

This option appealed to Abe, who decided to complete his current year in college and then pursue workplace training. He has agreed to contact his SAVTI coordinator when making this transition. The SAVTI coordinator will also contact Abe to ensure that a job search plan is developed and that connections are made with appropriate employers.

Appendix: Useful Resources

The books, journals and websites listed here will deepen your knowledge of cancer survivorship, and the approaches that have proven successful in supporting survivors of childhood cancer.

BOOKS

Educating the Child with Cancer: A Guide for Parents and Teachers. (2003) Nancy Keene, Editor. Candlelighters Childhood Cancer Foundation.

Childhood Cancer Survivors: A Practical Guide To Your Future. Nancy Keene, Wendy Hobbie, Kathy Ruccione; California; O'Relly Associates, Inc.: 2000.

WEBSITES

www.curesearch.org

www.candlelighters.org

www.candlelighters.ca

www.teenslivingwithcancer.org

www.pogo.ca/guide/savti.php

MINISTRY OF EDUCATION DOCUMENTS

The following documents are available on the Ministry of Education website at www.edu.gov.on.ca

Transition Planning: A Resource Guide, 2002

Co-operative Education and Other Forms of Experiential Learning: Policies and Procedures for Ontario Secondary Schools

Individual Education Plans: Standards for Development, Program Planning, and Implementation 2000

Teresa

TERESA WAS DIAGNOSED with Acute Lymphoblastic Leukemia (ALL) at age five and was treated with chemotherapy and cranial radiation. While attending school she had some difficulty in some subjects, particularly math and reading. Throughout high school she had an Individual Education Plan (IEP) which allowed for accommodations, including a quiet room and extra time for tests. Her parents also hired a tutor for math.

During high school, she had to work hard on assignments. She was also somewhat socially isolated, although she did have a small number of friends with whom she had a good relationship. She was referred to SAVTI while in Grade 12, because she was unsure of what she wanted to do after high school.

The SAVTI co-ordinator did some vocational assessments with Teresa and, through a series of appointments, determined some realistic options based on her interests and aptitudes. The choices that resulted were programs that allowed for practical hands-on experiences and did not have an onerous theoretical component.

Teresa had to take an extra year to complete her Grade 12 diploma and to complete two missing subjects that were required for college entry. With the help

of the SAVTI co-ordinator, Teresa applied to two colleges and was accepted at both. She chose to go to the college which was closer to home so that she could live with her parents. The next step was to ensure that she was in touch with the Disability Services. Here, she attended the orientation program for new students and met with the disability consultant.

Teresa is now in the second semester of a baking and pastry arts program. She is struggling and has to work hard, but she is passing and particularly enjoys the components of the program in which she is in the kitchen. She will take an extended period of time to complete the program, as her SAVTI coordinator has recommended a reduced course load. Through her contact with Disability Services, she has continued to receive accommodations – extra time and a quiet room for tests, as well as peer tutoring.

