



POPPI Newsletter

Pediatric Psycho-Oncology
Professionals/Providers
International

Issue 5: April 7th, 2020

STEERING COMMITTEE

WELCOME TO THE FIFTH ISSUE OF THE POPPI NEWSLETTER



Martha
Grootenhuis,
PhD. Chair
SIOP PPO



Claire
Wakefield,
PhD. Chair
IPOS peds
SIG



Lori Wiener,
PhD. Chair
APOS, peds
SIG



Sasja
Schepers,
PhD. Editor



Christina
Signorelli, PhD
Co-editor

A welcome note from the Chairs

by Martha Grootenhuis, Claire Wakefield, and Lori Wiener

Welcome to the fifth Issue of the POPPI Newsletter: Pediatric Psycho-Oncology Professionals/Providers International!

The goals of POPPI are to stimulate international communication among professionals with a diversity of clinical and research backgrounds in order to foster collaboration in clinical care, research and education that relate to pediatric psycho-oncology, and to share resources, training opportunities, ongoing research, and upcoming events in the field of pediatric psycho-oncology.

Our hope is that this newsletter will provide information which will bring our field closer together and help each of us to deliver the highest quality of care to youth with cancer and their families.

The COVID-19 pandemic has impacted all of our lives. Many of you may be making extraordinary sacrifices to care for your patients. Some of you may have become ill, be caring for family members, quarantined from your loved ones. We are all shifting our priorities and trying to model good coping strategies; not spread the contagion of anxiety. We will continue to share the impact of this pandemic on the pediatric psychosocial oncology community and lessons learned. As we all bear witness during this unprecedented time, please know that our thoughts are with all of you. Some resources to help support families impacted by cancer are provided on [page 11](#).

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Book release

A New Tool to Help Children Communicate about Death and Dying

By Lori Wiener & Meaghann Weaver, United States

Many of us use stories or books to help children address difficult issues. For children living with cancer, especially for those who might not survive their illness, storybooks can be a starting point for discussion, a safe way to ask questions or express concerns or worries. But in our search for such resources over the years, we found few and those that were available, didn't feel particularly helpful or meaningful.

To further this search, in 2017, Marina Colli, Meaghann Weaver, and Lori Wiener conducted a year-long extensive literature review in several languages in search of appropriate books for seriously ill children in the 6-12 age range. 210 books were reviewed. We found only 5 that could be directly relevant to a child who might not survive his/her condition. The one we liked the best was in French. We published our findings which included tables that exemplify ethnic diversity, the 5 books on a child's dying experience and a summary of 26 recommended books that address death and dying. We noticed that the majority of characters in the books were Caucasian and that there was a lack of diversity in worldviews or spiritual traditions represented in the books. Less than a quarter of

the books contained a guide or tool to help the reader interpret the meaning of the book and very few books actually used the words "death" or "dying".

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5704745/>

Equipped with a new awareness of the stark gaps in what was available through children's storybooks and recognizing the desperate communication needs among our pediatric patients at their own end of life, *The Gift of Gerbert's Feathers* was written. This is a story of a special gosling, named Gerbert. Gerbert loves his family, friends and geese community. Gerbert is also different than other geese his age. He is smaller, has different coloring, and does not share their good health. Through the pages of the book, the reader (and anyone reading the book to a child) is safely escorted through the psychological and behavioral process of preparing for a natural end of life through the tender perspective of this brave, dying gosling and his close community. Children are taught to find both comfort and confidence in this gentle gosling's open communication about his own death. And children discover that even when it feels that they are alone, they are never alone. Gerbert reaches children in a relatable way, giving permission for children to express their fears and

hopes and giving families the freedom to together acknowledge the child's communication needs with openness and compassion. Magination Press is the publishing house for the American Psychological Association. We chose Magination Press as they publish innovative books that help children deal with the many challenges and problems they face as they grow up. Magination Press found an exceptionally talented illustrator, Mikki Butterley, to bring the story to life.

The Gift of Gerbert's Feathers includes a note to readers on the first page. Sample discussion questions and online resources are available on the Magination Press website for parents, grandparents, siblings, friends and teachers to help sort through the feelings that might arise when reading through the pages of the book. A Kids Reading Guide, Fun Facts about Canadian Geese, and printable pages of feather drawings for coloring are also included. If there are any proceeds, they will go to the International Children's Palliative Care Network (ICPCN).

<https://www.maginationpressfamily.org/stress-anxiety-in-kids/talking-about-feelings-with-children-experiencing-serious-illness/>

<https://www.apa.org/pubs/magination/441B266?tab=4>



Research “in the spotlight”

Researcher in the spotlight: Dr Joanna Fardell

By Dr Joanna Fardell, Australia

Dr Joanna Fardell is a Fellow at UNSW Sydney and Sydney Children’s Hospital. In this issue, Joanna shares some of the research her team is working on.

As a Neuropsychologist by training, my research focuses on the educational outcomes and social-cognitive development of child and adolescent cancer survivors. Some of our earlier qualitative work found parents of childhood cancer survivors (as well as parents of children with other chronic illness) reported school absence and the experience of illness itself act as specific barriers to social connection. Parents felt their child often missed critical opportunities for social skill development and socialisation. The importance of school in establishing peer-social support was also widely acknowledged, yet many parents reported their child experienced anxiety about returning to school (Janin et al 2018).



Top row L to R:
Clarissa Schilstra (PhD Student), Jemima Hikila (Medical Student), Mary Burns (PhD Student)
Bottom from L to R:
Joanna Fardell & Sarah Ellis (Research Fellow)

We have recently completed recruitment for a project investigating the broader social-cognitive outcomes of long-term survivors of childhood cancer. Our initial data analysis suggests a proportion of survivors experienced bullying on return to school, consistent with the results of our systematic review on bullying (Collins et al 2019).

Survivors and parents reported verbal bullying (teasing) and social exclusion were common experiences due to differences in physical appearance and function, and social maturity. Survivors with cognitive difficulties were particularly vulnerable to bullying. We found school absence and lack of communication and understanding among peers were common correlates of bullying.

A final project which hopes to support young cancer patients and survivors is our Ready Steady School project. After several years in development with survivors and their parents, education providers in hospitals and school, and health care professionals, we have launched our education support website Ready Steady School. The Ready Steady School website provides tailored information, links to resources, and support strategies for childhood cancer patients and survivors, their parents and teachers, throughout the cancer-school journey. Our research project around this website aims to establish how acceptable and feasible tailored online information support offered through the Ready Steady School website is for ensuring education continuity across the cancer journey. We hope that by offering tailored information and support, communication between the child’s family, hospital and school about the child’s unique school and education needs is facilitated and students with cancer feel supported and connected to their school community.

Janin, M. M. H., et al. Parents’ perspectives on their child’s social experience in the context of childhood chronic illness: a qualitative study. *JPN*, vol. 42, pp.e10 - 18 <http://dx.doi.org/10.1016/j.pedn.2018.06.010>

Collins, D. E., et al. A Systematic Review Summarizing the State of Evidence on Bullying in Childhood Cancer Patients/Survivors. *JPON*. <https://doi.org/10.1177/1043454218810136>

Psychosocial Standards of Care Update

Evidence-based standards of care to be updated with implementation strategies

By Lori Wiener, United States

As noted in earlier POPPI newsletters, in 2015, the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC)—a large interdisciplinary group of expert stakeholders, published 15 evidence-based standards for pediatric psychosocial care. The Standards have provided centers a blueprint on what

evidence-based care should consist of. They are available to download for free at: <https://onlinelibrary.wiley.com/toc/15455017/62/S5>

Since the standards were published, we have had many requests for guidance on their implementation. In response, a **Matrix** (Institutional Scoring Measure) for each standard has been developed. Additionally,

Guidelines (how to) implement each of the standards has also been developed. The Guidelines include strategies and resources/tools to help sites improve their score on the Matrix and enhance their current practice. These have now been reviewed at 31 cancer centers are currently undergoing final revisions. Stay tuned for the final document which will be made available to all.

PPO conference news

Upcoming Pediatric Psycho-Oncology conferences

SAVE THE DATE - 2020

- International Psycho-Oncology Society (IPOS): August 12-15, 2020 in Kyoto, Japan.
- European Pediatric Psychology Conference: September 16-18, Stockholm, Sweden.
- The International Society of Pediatric Oncology (SIOP) 52nd Annual Meeting: October 14-17, 2020 in Ottawa, Canada.

Conference updates

51st SIOP Congress 2019

By Kelly van Bindbergen, The Netherlands

From SIOP PPO: A retrospect on the Educational Day in Lyon

Thank you to everyone who attended the PPO Educational Day of SIOP in Lyon. For this day, 95 colleagues registered from 32 different countries, and many of our session were visited by a much larger audience. From all the abstracts that we submitted, 17 abstracts were selected to be presented in one of our sessions on Adolescents and Young Adults, School and Education, Decision Making and a Breakout session with mixed topics.

Additionally, keynote speaker Lamia Barakat gave us a very

impressive overview of the current knowledge on Interventions in Effectiveness Research, showing us there is more to it than just randomized controlled trials and p-values!

Her talk was followed by a lively and in-depth Panel discussion on the alternatives, providing us with thought provoking ideas from panelists Anne Kazak, Sean Phipps, Maru Barrera, and Claire Wakefield together with Lamia Barakat and Maria McCarthy.

Another interesting and very well attended keynote talk was from Anne-Sophie Darlington on Adolescents and Young Adults, which showed us the uniqueness of their experiences regarding quality of life, and the different types of adolescents and young adults that

exist: AYAs (diagnosed between the age of 18-30), AYA survivors (diagnosed between the age of 18-30, but survivor of a AYA diagnosis) and YACCS (18-30 year old childhood cancer survivors).

We finished our day with discussing two very intriguing Clinical Cases presented by Jurgen Lemiere and Nicole Schneider, which both had a large impact on the audience.

We believe that the PPO Educational Day had many highlights and a wide variety in topics and sessions, which made the day a great success. We are looking forward to seeing you all again in Ottawa, Canada for the Educational Day of SIOP this year!



17th APOS Conference

By Lori Wiener, United States

Unfortunately, due to COVID-19, this meeting was cancelled. However, exciting oral sessions have been and will continue to be recorded. They will be available to registered conference attendees for 90 days.

Sessions that might be of interest to POPPI readers are:

- Suicide Risk in Patients with Cancer Across the Lifespan
- Pediatric Psychosocial Standards of Care: Innovative Methods to Reduce Implementation Barriers

- Adolescent and Young Adult Training Competencies for the Psychosocial Provider

- Music Therapy for Children with Cancer and Their Families: Advancing the Standards for Psychosocial Care

- Substance Use Behaviors in Adolescent and Young Adult Cancer Patients: Associations with Mental and Physical Health

- Feasibility and Acceptability of Enrolling Pediatric Patients with a Life Threatening Disease Into an Integrative Medicine Trial: Lessons Learned

- A Randomized Pilot Trial of an mHealth Physical Activity Intervention for Adolescent and Young Adult Cancer Survivors: Feasibility, Acceptability, and Psychological Well-Being Outcomes



21st IPOS World Congress

By Claire Wakefield & Christina Signorelli, Australia

The new dates for the 22nd World Congress of the Psycho-Oncology & Psychosocial Academy have been announced. The meeting has been postponed from June 2020, and will now be held on August 12-15, 2020 in Kyoto, Japan.

The venue remains the same: the International Conference Centre, Kyoto.



The conference theme is “Diversity, Dialogue and Altruism: To achieve universal psychosocial care for all”, reflecting the IPOS mission which is to promote the psychosocial care of all people affected by cancer through collaborative efforts, awareness, research, and public policy.

The call for abstracts for symposiums, and oral and poster presentations is now open. Submissions are due by May 31, 2020 (deadline extended from March 1).

This year the Early Career Professionals In Psycho-Oncology (ECP) committee will organize a several events for early career

professionals including mentoring sessions, research grant development, a SIG meeting and social event.

All Psycho-Oncology professionals within ten years of their highest degree, such as postgraduate or PhD students, clinicians or postdocs are welcome to participate.

The “Early-bird” registration deadlines for the conference have been revised to May 15, 2020. The IPOS and World Congress Committee are constantly monitoring the impact of the coronavirus globally.

Please check the IPOS website for regular updates on changes to the Congress:

<http://ipos2020.com/index.html>

Zambia National Stakeholder Workshop on Childhood cancer

By Benedict Akimana, Uganda

I am excited to share my travel experience to Zambia to represent the International Psycho-oncology Society (IPOS) at the Zambia National Stakeholder Workshop on Childhood Cancer which took place on February 13th, 2020. I would like to thank IPOS for making my travel possible on short notice and St Jude Children’s Hospital for hosting me.

The meeting was well attended with representatives from the Zambia ministry of health, WHO country representative, International Atomic Energy Association, International Society of Pediatric Oncology, childhood cancer survivors and clinicians from neighboring African countries and world over.

The goal of the workshop was to connect National priorities to commitments and global targets. Objectives were to summarize

the current landscape and priorities for cancer control in children and adolescents in Zambia, introduce the concepts of WHO CURE All and defining core projects to accelerate progress for children and adolescents with cancer in Zambia between 2020-2023.

The day’s event was very successful with the various stakeholders affirming their commitment towards ensuring that every child and adolescent with cancer has access to adequate treatment and care.

Among the highlights was a testimony from a cancer survivor who shared her experience through

the treatment process in India, she noted how difficult it was for her losing most of her friends on the ward, how her mother had to act strong, yet deep down she saw how distressed and helpless she was but had to soldier on!

Notably, the psychosocial well-being of persons with cancer is not given as much attention especially in our African setting, but we are happy with the direction that IPOS has taken to support psycho-oncology in LMIC. A note of progress - since the beginning of February, the Zambian psychiatry team has started ward rounds to the cancer wards. Kudos!



International Exchange

By [Niki Rensen](#), *The Netherlands*



My name is Niki Rensen, I am a physician by training and currently finishing my PhD on sleep, distress and quality of life in parents of

children with cancer at the Princess Máxima Center and Amsterdam UMC (The Netherlands). I am supervised by Dr Raphaële van Litsenburg, Prof Gertjan Kaspers and Prof Martha Grootenhuis.

From June 2020, I will move to Sydney for a one-year research fellowship at the Behavioral Sciences Unit (BSU), Kids Cancer Center. Under supervision of prof. Dr. Claire Wakefield and Dr. Kate

Hetherington, I will write up data on sleep and psychosocial functioning of bereaved parents that has been collected as part of the Compass study. During my PhD, I was involved with two large scale studies on parental functioning that did *not* include bereaved parents; hence, the project at the BSU will be a valuable addition to my previous work.

Furthermore, since the BSU and Kids Cancer Center have considerable experience with conducting bereavement research and with bereavement support services (which we have not yet routinely implemented in the Netherlands), I hope to bring back both scientific and clinical knowledge.

In Sydney, I will also be involved with assisting in the ongoing

development and implementation of the CBT-based, online group intervention CASCADE (Cope, Adapt, Survive: life after CAnCEr), targeted at parents of childhood cancer survivors.

Considering my experience with research into parental sleep, I will work together with the team at the BSU to consider whether CASCADE can be expanded to include sleep as a theme, with the ultimate goal of supporting parents the best way possible. In summary, my visit will provide the opportunity to further develop the valuable international collaboration between researchers at Princess Máxima and UNSW. I am looking forward to it!

Niki's visit will be postponed for a few months, due to the COVID19 pandemic.

PPO theses from around the globe

International PhD Candidates and recent graduates in the field share their theses

By [David Mizrahi](#), *Australia*



Thesis title: *Investigating the role of physical activity among survivors of childhood cancer.*

As the survival rate for childhood cancer increases, the cost of cure leaves this population at-risk for developing cardio-metabolic late-effects during

survivorship. Yet, understanding potential health protective behaviours including physical activity and cardiorespiratory fitness to mitigate this risk remains limited.

For my thesis, I investigated physical activity and cardiorespiratory fitness levels among survivors. The majority (73% children, 70% adults) from 11 Australia/New Zealand pediatric oncology hospitals didn't meet recommended physical activity guidelines. I investigated cardiorespiratory fitness and developed an algorithm using the 6-minute walk test, waist-to-height ratio, age and sex to predict maximal oxygen consumption (gold-standard measure), establishing that fitness levels were low (37th percentile). Survivors reported fatigue, preferring TV and lacking time as physical activity barriers, whilst active survivors more

likely exercised with friends.

Parents and survivors were more satisfied with receiving an exercise physiology consultation including individualised exercise prescription compared with their usual care (no consultation). Nearly all parents and survivors expressed demand for additional exercise physiology consultations for themselves and future survivors. Despite this demand, logistical barriers including distance to facilities affect the feasibility of supervised interventions. Hence, my systematic review and meta-analysis exploring distance-delivered physical activity interventions (e.g. telephone, internet, mobile applications) found most survivors adhered to prescribed distance-delivered physical activity and remained in programs, yielding improvements in physical and psychological health.

In conclusion, my thesis demonstrated that childhood cancer survivors require support to increase physical activity and cardiorespiratory fitness to mitigate their already increased risk of medical late-effects. I will continue researching pediatric exercise-oncology at St. Jude Children's Research Hospital (Tennessee, USA) on a Fulbright Fellowship from June.

Dissertation Link:

<http://handle.unsw.edu.au/1959.4/63308>

By Tineke Vandenbroucke, Belgium



Thesis title: *Cancer during pregnancy: Impact on neuropsychological child development and on the couple's distress and coping.*

When cancer is diagnosed in an expecting mother, the decision whether or not to start treatment strikes a delicate balance between the well-being of the mother and that of the fetus. The primordial concern is the possible exposure of the fetus to imaging, surgery, chemotherapy, radiotherapy and the associated stress, with potential ensuing toxic effects. Many physicians remain reluctant to start cancer treatment during pregnancy because of the lack of evidence on short- and long-term safety for the fetus. Moreover, a cancer diagnosis during pregnancy may be considered as an emotional challenge for the expecting parents.

To date, there is a lack of knowledge about the concerns and distress these women and their partners experience, how they deal with these concerns and who is at risk for high levels of distress. The PhD project focused on two lines of research: In the first line of research, we investigated the cognitive development and behavior of children born to mothers diagnosed with and treated for cancer during pregnancy. At the age of 18 months, 3 years, 6 years and 9 years, the children were subjected to a comprehensive neuropsychological test protocol, including a test for general cognitive development (at the age of 18 months and 3 years) or intelligence, attention and memory tests and a behavior questionnaire (at the age of 6 and 9 years). The results were compared to those of a control group of children who were born after an uncomplicated pregnancy and delivery. The control children were one-to-one matched to the study group

for gestational age at birth, test age, country and at the age of 6 and 9 years also for gender and language of the tests. We found that the cognitive development and behavior of children born to mothers diagnosed with cancer (and treated with surgery, chemotherapy and/or radiotherapy during pregnancy or not treated during pregnancy) were in general comparable to the cognitive development and behavior of the control group. However, Full Scale and Verbal IQ were significantly lower in the study versus control group at the age of 6 years, although the values were within the normal range and these differences were not found in our interim analysis of 9-year-old children. Further research in larger samples and at older ages is needed to evaluate the evolution of these findings.

In the second line of research, we investigated the impact of the diagnosis and treatment of cancer during pregnancy on the psychological distress and use of cognitive coping strategies in pregnant women and their partners. Our study indicated that the diagnosis of cancer may be an emotional challenge for pregnant women and their partners, which is associated with concerns about the child's health, about the disease and treatment and about the pregnancy and delivery.

We found that especially women and their partners who mainly use internalizing coping strategies to deal with their cancer diagnosis and treatment (e.g., rumination, catastrophizing, refocus on planning, blaming self and others, a lack of acceptance and of positive refocusing) deal with the highest levels of concerns and distress and may benefit from additional psychosocial support.



Dissertation link:

<https://drive.google.com/file/d/1BUoNdV0UM-p5T4nP2CHAH1H8xqJIZUC/view?usp=sharing>

By Charlotte Sleurs, Belgium



Thesis title: *Neurotoxicity and potential risk factors in childhood solid tumour patients.*

As survival rates of childhood cancer patients improved throughout the last decades, long-term sequelae such as neurocognitive impairment after treatment became an important area of research. Neurosurgery, cranial radiotherapy (RT) and central nervous system (CNS) directed chemotherapy are known to lead to neurocognitive alterations in childhood brain tumor and leukemia patients.

By contrast, in solid non-CNS tumor patients, findings about potential neurotoxicity due to intravenous chemotherapy only, remain limited. Nevertheless, case reports showed that even (high-dose) intravenous chemotherapy can induce acute leukoencephalopathy and neurological symptoms. In this PhD project, Sleurs et al. investigated chemotherapy-induced neurotoxicity. The thesis suggests widespread acute and long-term neural damage due to high-dose intravenous chemotherapy in childhood sarcoma patients, which can highly affect their neurodevelopment throughout childhood. Multiple neural changes were found in both

current patients and adult survivors, including altered white matter fiber density, decreased grey matter density and cortical thickness and declines in processing speed. In addition to sarcoma studies, the thesis reports brain network reorganization in case of acquired brain injury, which is the case in posterior fossa tumor patients. Specifically, strongly connected brain areas (called hubs) appeared mostly affected in these patients, which was strongly associated with decline in intelligence scores. To address subject-specific vulnerability, future studies are required including (pre-) clinical biochemical biomarkers in order to clarify altered synaptogenesis, neurotransmission and/or metabolite changes. Longitudinal designs are recommended to investigate developmental and degeneration patterns over time.

At the prospect of advanced treatment techniques, the long-term goal of this research domain is to reduce neurotoxicity, e.g. by decreasing/fractionating the doses of toxic chemotherapy and cranial radiotherapy, adding neuroprotective medication and neurorehabilitation, providing subject-specific psychosocial support; in order to improve the long-term quality of life in survivors of childhood cancer.

Dissertation link:

https://drive.google.com/open?id=1UCYfjJnx8ueiy7ERFwhu_Mm52VXXeBIC

Recent PPO publications

Recently published articles in *Psycho-Oncology* (official journal of APOS & IPOS), *Pediatric Blood & Cancer* (official journal of SIOP), and the *Journal of Psychosocial Oncology Research & Practice* (official journal of IPOS):



Pediatric Blood & Cancer publications

Christen et al., ["I wish someone had once asked me how I'm doing": Disadvantages and support needs faced by parents of long-term childhood cancer survivors.](#)

Desrosiers et al., [Integrating genetic counseling and testing in the pediatric oncology setting: Parental attitudes and influencing factors.](#)

Ebsenshade et al., [Mentors' perspectives on the successes and challenges of mentoring in the COG Young Investigator mentorship program: A report from the Children's Oncology Group.](#)

Essig et al., [Communicating "cure" to pediatric oncology patients: A mixed-methods study.](#)

Frederick et al., [A qualitative study of sexual and reproductive health communication with adolescent and young adult oncology patients.](#)

Grace et al., [Evaluating and providing quality health information for adolescents and young adults with cancer.](#)

Graetz et al., [Things that matter: Adolescent and young adult patients' priorities during cancer care.](#)

Harrington et al., [Multimorbidity and healthcare utilization among early survivors of pediatric cancer.](#)

Levin et al., [Psychosocial issues for adolescent and young adult cancer patients in a global context: A forward-looking approach.](#)

Jatia et al., [Holistic support coupled with prospective tracking reduces abandonment in childhood cancers: A report from India.](#)

Kazak et al., [A psychosocial clinical care pathway for pediatric hematopoietic stem cell transplantation.](#)

Kenney et al., [Regional practice norms for the care of childhood cancer survivors at risk for cardiomyopathy: A Delphi study.](#)

McGill et al., ["I remember how I felt, but I don't remember the gene": Families' experiences of cancer-related genetic testing in childhood.](#)

Morell et al., [Dietary intake and micronutrient deficiency in children with cancer.](#)

Mueller et al., [Identifying patient-centered outcomes for children with cancer and their caregivers when they seek care in the emergency department.](#)

Peterson et al., [Predictors of neuropsychological late effects and white matter correlates in children treated for a brain tumor without radiation therapy.](#)

Phillips et al., [Health-related Google searches performed by parents of pediatric oncology patients.](#)

Raghubar et al., [Adaptive functioning in pediatric brain tumor survivors: An examination of ethnicity and socioeconomic status.](#)

Rogers et al., [A pilot randomized controlled trial to improve sleep and fatigue in children with central nervous system tumors hospitalized for high-dose chemotherapy.](#)

Sharkey et al., [The relationship of child executive functions to parenting capacities in childhood acute lymphoblastic leukemia survivors.](#)

Sisk et al., [Ethical issues in the care of adolescent and young adult oncology patients.](#)

Sleurs et al., [Long-term leukoencephalopathy and neurocognitive functioning in childhood sarcoma patients treated with high-dose intravenous chemotherapy.](#)

Spreatico et al., [Sport activities and exercise as part of routine cancer care in children and adolescents.](#)

Steineck et al., [Psychosocial care for children receiving chimeric antigen receptor \(CAR\) T-cell therapy.](#)

Stoneham et al., [AYA testis cancer: The unmet challenge.](#)

Streefkerk et al., [The involvement of primary care physicians in care for childhood cancer survivors.](#)

Touyz et al., [Childhood cancer survivors report preferring lifestyle interventions delivered in person rather than online: An adolescent and parent perspective.](#)

Van Warmerdam et al., [Prevalence of anxiety, depression, and posttraumatic stress disorder in parents of children with cancer: A meta-analysis.](#)

Journal of Psychosocial Oncology Research & Practice publications

Shunmugasundaram, C et al., [Caregivers' perception of psychosocial issues of pediatric patients with osteosarcoma: an exploratory study.](#)

Continued over the next page...

Psycho-Oncology publications

Ahuja et al., [A pilot study to determine out-of-pocket expenditures by families of children being treated for cancer at public hospitals in New Delhi, India.](#)

Aziza et al., [Unmet supportive care needs and psychological distress among parents of children with cancer in Indonesia.](#)

Carlsen et al., [Adaption strategies used by siblings to childhood cancer patients.](#)

Chung et al., [The feasibility and value of parent input when evaluating the mental health of young adults with and without cancer.](#)

Daniel et al., [A call to action for expanded sleep research in pediatric oncology: A position paper on behalf of the International Psycho-Oncology Society Pediatrics Special Interest Group.](#)

D'Souza et al., [Internalizing symptoms in AYA survivors of childhood cancer and matched comparisons.](#)

Ernst et al., [Parenting in the face of serious illness: Childhood cancer survivors remember different rearing behavior than the general population.](#)

Faith et al., [Parents' emotion socialization beliefs moderate relations between parent and patient coping, but not sibling coping, with pediatric cancer.](#)

Gerhart et al., [Posttraumatic stress disorder and posttraumatic growth in a national sample of pediatric oncology professionals.](#)

Gessler et al., [Clinician-patient-family decision-making and health literacy in adolescents and young adults with cancer and their families: A systematic review of qualitative studies.](#)

Geue et al., [Anxiety and depression in young adult German cancer patients: Time course and associated factors.](#)

Gittzus et al., [Peace of mind among adolescents and young adults with cancer.](#)

Gotze et al., [Fear of cancer recurrence across the survivorship trajectory: Results from a survey of adult long-term cancer survivors.](#)

Hungr et al., [Utilization of integrated psychosocial care in a pediatric cancer survivorship clinic: A retrospective medical record review.](#)

Lau et al., [Exploratory analysis of treatment response trajectories in the PRISM trial: Models of psychosocial care.](#)

Perez et al., [Barriers to care in pediatric cancer: The role of illness uncertainty in relation to parent psychological distress.](#)

Pohlkamp et al., [Bereaved mothers' and fathers' prolonged grief and psychological health 1 to 5 years after loss-A nationwide study.](#)

Ramsey et al., [eHealth and mHealth interventions in pediatric cancer: A systematic review of interventions across the cancer continuum.](#)

Ricadat et al., [Adolescents and young adults with cancer: How multidisciplinary health care teams adapt their practices to better meet their specific needs..](#)

Robertson et al., [Piloting a parent and patient decision aid to support clinical trial decision making in childhood cancer.](#)

Roser et al., [The impact of childhood cancer on parents' socio-economic situation-A systematic review.](#)

Schwartz et al., [Feasibility and acceptability of a pilot tailored text messaging intervention for adolescents and young adults completing cancer treatment.](#)

St George et al., [Development of a multigenerational digital lifestyle intervention for women cancer survivors and their families.](#)

Stafford et al., [Why did we fail? Challenges recruiting parents with cancer into a psycho-educational support program.](#)

Tilley et al., [Impact of the parent-child relationship on psychological and social resilience in pediatric cancer patients.](#)

Weeks et al., [A summary of high quality online information resources for parents with cancer who have adolescent and young adult children: A scoping review.](#)

Have you recently published a relevant paper in *Pediatric Blood and Cancer*, *Psycho-Oncology* or the *Journal of Psychosocial Oncology Research & Practice* that you would like us to include in the next issue? [Contact us!](#)

CANCER AND COVID-19

Pandemics, social distancing, & getting stuff done: Reflections from an AYA cancer survivor.

By Clarissa Schilstra, Australia

In 2007, I was 13 years old. Instead of starting high school, I was starting a 2 ½ year treatment for relapsed Acute Lymphoblastic Leukaemia (ALL). The whole goal of the first year of my treatment was to get my white blood cell count down to 0, or at least as close to 0 as possible, to ensure any leukaemia cells were not left hanging around. That meant that I essentially had 0 immune system for more than one year. With no immune system, you learn very quickly that the #1 rule is to AVOID ALL THE GERMS. That meant I had to avoid attending school, or seeing friends or relatives who had any symptoms of a viral or

bacterial infection. One of the second things you then learn is how much you took for granted going to school or work. As I got towards the end of my treatment, in early 2009, I was inching my way closer to freedom and returning to school. But, my plans were thrown out the window as the H1N1 influenza (also known as Swine Flu) pandemic took over the US (where I lived at the time). After discussion with my doctor, my parents and I decided that I should stay home and avoid attending school for a few more months. This was perhaps the most difficult time because I was finally physically feeling better, so I felt the limitations even more.

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11 years later, all of the hype around social distancing feels strange because I've seen how cancer patients, survivors, and anyone living with an immunocompromising condition, have been social distancing pros for years already. It's just that social distancing wasn't Instagram-able until the rest of the world had to do it too. So, if you're struggling with the idea of social distancing and how you'll cope with the foreseeable future in isolation, reach out to someone with experience (Just not in-person!). I'm sure they'll have lots of useful advice to share! In case you don't know anyone with this kind of expertise, or if you're



newly living with a socially-limiting illness yourself, I'll share with you my top 5 pieces of advice for how to manage life at home, on

your own.

1. Have an accountability buddy or find ways to hold yourself accountable for your work. While I was on treatment, I was lucky to have a home/hospital tutoring program provided by my county in the US. This meant that they sent a teacher to my school to pick up my assignments from my school teachers, spend 6 hours per week in my home and go through new lessons with me. For the other 34 hours, I had to get through assignments on my own. But, expecting my teacher's visit on the same days each week meant that I had someone holding me accountable.

Alternatively, if you don't have someone to hold you accountable, consider setting some deadlines for yourself. Make a schedule for yourself - including time for things you enjoy or other tasks that you need to do around your home. Days without structure can seem fun at first, but soon they become frustrating and can contribute to a sense of hopelessness/lack of accomplishment. On the other hand, too much work can burn you out. Your brain will take some time to acclimate to being on its own (it's amazing how much harder it is to work when you're not surrounded by other people working). You might also have distractions around you to navigate. Consider these things when making a schedule for

yourself, and possibly consult your teachers or supervisors. Making a schedule will also help you protect your personal time so you can do some things you enjoy in your free time.

2. Ensure you plan at least one achievable task/goal each day. When you're stuck at home, it can be really helpful to get some sense of accomplishment each day, to remind you that you are making good use of your time. I always found it useful, as I started each day, to choose one achievable task that I knew I could and would get done that day. That way, whether fatigue limited my work hours or chemo-brain limited by working speed, I could still say I got something done.

3. Pay attention to your feelings and talk about them - virtually with friends, or in person with people living with you. Being at home 24 hours per day, 7 days per week gets old. Really fast. You'll find yourself having moments of loneliness, frustration, boredom, lack of focus, etc. Pick up the phone and call a friend or relative. Use your video call service of choice to connect with your workmates or classmates. You can be physically isolated but you don't have to be socially isolated! Also, remember that distancing and isolation don't last forever. Whether you have to make it through flu season, a pandemic, or 2.5 years of cancer treatment, remind yourself that you just have to keep moving forward.

4. Choose a single space in your home as your workspace. When I was sick, it was my parents' dining room table. We extended it out as far as it would go, then I took over half of it. Pick a space with as much natural light as possible, and preferably with a window nearby - it'll help you keep awake and focused. Try to separate your work space from your leisure space where possible - like I try to limit my use of my kitchen table to work and meal times.

5. Instead of letting this adversity become problematic, it's a great time to consider how we can find new opportunities - opportunities for each of us to learn more about ourselves, spend more time with those we live with, learn new hobbies or skills, test out new ways of working and getting things done, or helping others who may be struggling. By social distancing, we may find better ways of getting and staying connected to one another. Most importantly, we won't take for granted how lucky we are when we can get up in the morning and leave our homes to go to work or school.

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POPPI
Newsletter
Our next newsletter will
be circulated in August
2020.

All feedback and suggestions are welcome!

If you have any questions relating to the newsletter content, or if you would like to make a contribution to future newsletters, please contact the Editor [Sasja Schepers](#).

CANCER AND COVID-19

Helpful resources for healthcare providers and families

Online Support Groups

Cancer Care (USA)

<https://www.cancercaresupportgroups.org/>

Macmillan Cancer Support live chat (UK):

<https://public.mc.hostedcc.com/MacmillanCancerSupport/forms/Chat/SLSChat>

American Cancer Society (live chat):

<https://livechat.boldchat.com/aid/5386287375352862963/bc.chat?resize=true&cwidid=1134019502191338137&url=https%3A//www.cancer.org/&url=https%3A//www.cancer.org/>

Coping Strategies for Parents and Children

Children's Cancer Cause:

<https://www.aets.org/helping-children-cope-emotionally-with-coronavirus?fbclid=IwAR0QfdSPQqeD7L33FCgru-Y00g0E-jlpeEdQPj07QsRomTeLz4mp72QxyOk>

Chai Lifeline:

<https://blog.chailifeline.org/coronavirus-quarantine-faqs/>

British Psychological Society - how to talk to children about COVID-19:

<https://www.bps.org.uk/news-and-policy/bps-highlights-importance-talking-children-about-coronavirus>

Children's Oncology Group (for survivors of childhood and AYA cancers):

English:

https://www.childrensoncologygroup.org/downloads/COVID-19_and_Your_Child_with_Cancer_English_3.20.20.pdf

Spanish:

https://www.childrensoncologygroup.org/downloads/COVID-19_and_Your_Child_with_Cancer_Spanish_3.20.20.pdf

Information for Parents of Children with Cancer

Alex's Lemonade Stand:

<https://www.alexlemonade.org/blog/2020/03/how-protect-children-cancer-tips-during-covid-19-season>

Children's Cancer Cause:

<https://www.childrenscancercause.org/covid19>

Adolescent and Young Adult Information

Stupid Cancer (webinar):

<https://stupidcancer.org/covid-19-concerns/>

General Information for Cancer Patients and Caregivers

American Cancer Society:

<https://www.cancer.org/about-us/what-we-do/coronavirus-covid-19-and-cancer.html>

American Society for Clinical Oncology (English and Spanish):

<https://www.cancer.net/blog/tags/coronavirus>

Cancer Care (USA):

<https://www.cancercaresupportgroups.org/tagged/coronavirus>

Cancer Support Community:

<https://www.cancersupportcommunity.org/blog/2020/03/what-cancer-patients-survivors-and-caregivers-need>

National Cancer Institute:

<https://www.cancer.gov/contact/emergency-preparedness/coronavirus>

Information for Transplant Recipients

BMT Infonet (webinar and transcript):

<https://www.bmtinfonet.org/video/coronavirus-what-transplant-recipients-need-know>

Information for Cancer Patients in Australia and New Zealand:

<https://anzchog.org/covid-19-guidance-for-children-and-young-people-undergoing-cancer-treatment/>

<http://cancercentreforchildren.org.au/coronavirus-update-cancer-centre-children>

Helplines (United States, Australia and Europe)

American Cancer Society (24-hour helpline): 800-227-2345

Cancer Care Hopeline: 800-813-4673

Macmillan Cancer Support: 0808 808 00 00

Cancer Research UK (nurse helpline): 0808 800 4040

Irish Cancer Society Nurseline: 1800 200 700

International Coronavirus Helplines:

France: 0800 130 000

Belgium: 0800 14 689

The Netherlands: 0800 1351

United Kingdom: 0800 024 1222

Australia: 1800 020 080

Financial Assistance

<https://www.cancercaresupportgroups.org/financial>