



CANADIAN  
PARTNERSHIP  
AGAINST CANCER

# Approaches for Addressing Mental Health & Return to Work Needs of Cancer Survivors

AN ENVIRONMENTAL SCAN

JULY 2019

## Acknowledgements

---

This report was prepared by Dale McMurchy Consulting for the Person-Centered Perspective and Prevention Program with the Canadian Partnership Against Cancer.

## Suggested Citation

Canadian Partnership Against Cancer. Approaches for Addressing Mental Health & Return to Work Needs of Cancer Survivors: An Environmental Scan. Toronto, Ontario, Canada: Canadian Partnership Against Cancer, 2019 July.

ISBN: 978-1-988000-44-2 (Online)

The contents of this document have been made possible through a financial contribution from Health Canada, through the Canadian Partnership Against Cancer. The views expressed herein represent the views of the Canadian Partnership Against Cancer.

## Contents

Executive Summary .....	i
Summary of Key Findings.....	i
Cancer Survivorship Mental Health and Psychosocial Needs .....	i
Cancer Survivorship Service Priorities .....	ii
Survivorship Care Pathways .....	iii
Survivorship Program Models .....	iv
Levels of Psychosocial Needs.....	vi
Higher Acuity Mental Health and Psychosocial Services .....	vi
Higher Acuity Interventions.....	vi
Topic-specific Interventions .....	vii
Online Interventions.....	viii
Primary Care.....	ix
Return to Work.....	ix
Conclusion .....	x
Background.....	1
Methods .....	1
Objective .....	1
Literature and Program Review.....	1
Case Studies and Key Informant Interviews .....	1
Findings .....	2
Survivorship Needs.....	2
Cancer Survivorship Care Priorities and Guidelines .....	4
Program Design.....	6
Program Development.....	6
Key Program Design Features .....	7
Funding .....	10
Program Monitoring and Improvement .....	10
Survivorship Program Models .....	11
Standalone Multimodal Programs within Cancer Centres.....	11
Embedded Services.....	12
Community-Based and Regional Programs .....	12
Psychosocial Services .....	14
Service Targets and Stratification.....	14
Low Risk .....	15
Self-Management .....	15
Types of Peer Support.....	17
Individual Peer Support .....	17
Peer Support Groups.....	18
Group Educational Sessions .....	19

Online Information and Educational Support.....	20
Higher Risk .....	21
Targeted Psychosocial Programs.....	23
Individual.....	23
Group .....	24
Online Mental Health Interventions .....	25
Mindfulness and Spiritually .....	26
Physical Activity .....	28
Exercise .....	28
Rehabilitation .....	29
Primary Care.....	30
Follow-up Care in the Community .....	30
Survivorship Care Plans (SCPs).....	31
Integrated Frameworks and Models for Continued Cancer Care in Primary Care.....	32
Return to Work.....	33
Return to Work Needs .....	33
Return to Work Interventions .....	34
Individual and Group Interventions.....	35
Primary Care.....	37
Web-based Interventions.....	37
Publications.....	39
Conclusion .....	40
Appendix A - Key Informants.....	42
Appendix B - List of Case Studies .....	44
Appendix C - Inventory of Cancer Survivorship Programs List .....	46
Appendix D - Inventory of Other Chronic Disease Programs List.....	51
References .....	52

## Tables

Table 1. Pan-Canadian recommendations and guidance on psychosocial supportive care for adult cancer survivors.....	5
Table 2. Psychosocial measurement tools .....	8
Table 3. Living with and Beyond Cancer Programme stratification guidelines for breast cancer .....	9
Table 4. Examples of trade-marked group survivorship educational programs .....	19
Table 5. Evidence-based interventions for cancer-related distress .....	21

## Figures

Figure 1. Symptoms of at least moderate severity reported by cancer survivors .....	4
Figure 2. National Cancer Survivorship Initiative Stratified Model of Care .....	9
Figure 3. Targets of psychosocial oncology interventions.....	14
Figure 4. Tiered model of psychosocial need and care.....	15
Figure 5. Conceptual framework for cancer self-management .....	166
Figure 6. Spectrum of mental health peer support .....	177
Figure 7. Determinants associated with returning to work after breast cancer .....	34
Figure 8. Case management conceptual model for return to work .....	35

## Executive Summary

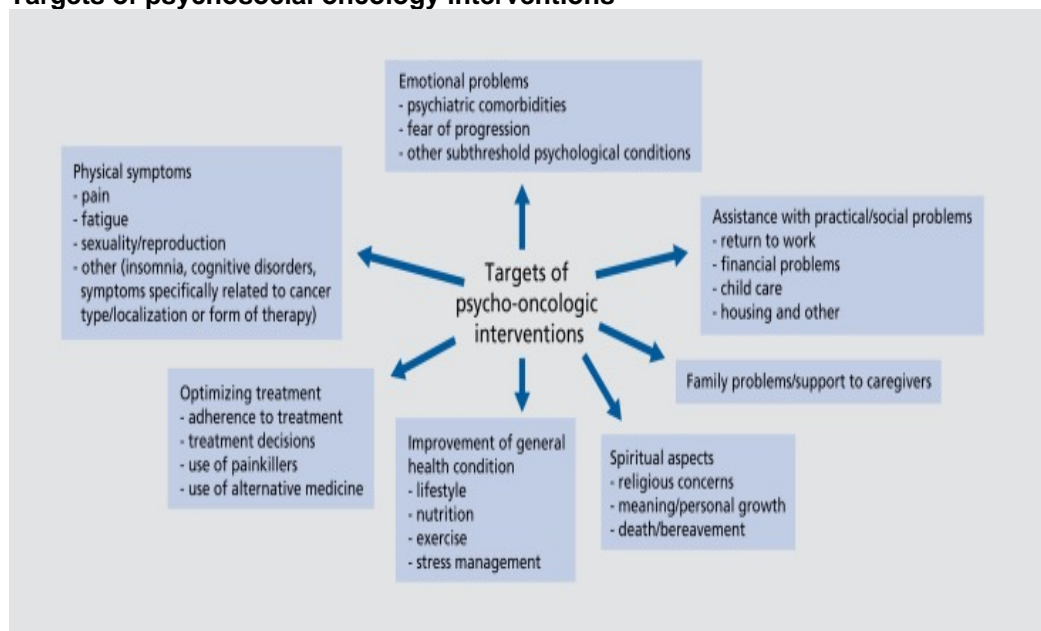
### Summary of Key Findings

- Despite increasing recommendations and guidelines for interventions that address cancer survivors' unique physical, psychosocial and mental health needs, many do not receive adequate support as they transition back to their daily lives and many of their needs remain unmet. Few receive survivorship care plans.
- Many program representatives report that psychosocial services are in high demand in cancer centres and tend to focus on patients during cancer treatment.
- Even those offered access to survivorship programs may experience barriers to accessing them due to time limitations, distance, resources and their socioeconomic status.
- Five key themes emerge from the recommendations and guidelines for survivorship programs: i) holistic needs assessments; ii) identifying survivors' unique goals and priorities; iii) individualized survivorship care plans; iv) tiered or risk-stratified pathways tailored to individual risk profiles and stated needs; and v) seamless transitions and coordination of care.
- Given the diverse needs of cancer survivors and the results of several studies, experts support a multimodal, interprofessional and, in some instances, multi-agency approaches to survivorship programs. Such programs have been associated with greater patient experience; closer adherence guidelines; increased attendance at various survivorship services; reduced recurrence; and improved survivor wellbeing.
- Many survivors with low- to moderate-level psychosocial risk have been shown to benefit from relatively low-intensity peer, group, telephone and web-based interventions, including self-help education, individual and group peer support, educational sessions and physical activity.
- Cancer survivors with a higher acuity of mental health and psychosocial concerns may require more intensive professionally-led psychosocial counselling or topic-specific interventions. Referrals can be within a survivorship program, cancer centre or hospital, or to the community.
- Online services have been shown to address survivors' needs in an acceptable, accessible, cost-effective and convenient manner.
- Primary care plays an important role in the cancer care continuum. Family physicians and their patients support a greater role for primary care in follow-up care, but there are several patient, provider and health system barriers to transitioning effectively to primary care, including the flow of information, coordination and continuity of care, varied guidelines, and the readiness and capacity of primary care.
- Several programs may touch on return to work in their educational programs, but few provide dedicated one-on-one or group support for return to work challenges.

### Cancer Survivorship Mental Health and Psychosocial Needs

Cancer survivors experience a variety of late or long-term effects from their illness and its treatment, which depend on the individual, type of cancer, treatment regimen and time since treatment ended. In addition to ongoing monitoring of their physical health, including screening and prevention of recurrence, many working-age survivors need supportive interventions that address their unique psychosocial and mental health needs. As shown in the figure below, these needs can vary in nature, complexity and severity. Despite increasing recommendations and guidelines for such care, many cancer survivors do not receive requisite support as they transition back to their daily lives and many of their needs remain unmet.

## Targets of psychosocial oncology interventions



(Lang-Rollin, 2018)

To address this gap in the continuum of cancer care, the Canadian Partnership Against Cancer commissioned an environmental scan detailing Canadian and international mental health and return to work models of care, programs and services for survivors. The environmental scan entailed searches of national and international published and unpublished literature related to cancer survivorship, web-based searches of survivorship programs, interviews with experts in cancer survivorship and program administrators, and questionnaires completed by representatives of selected programs to inform the content of this report and develop case studies and inventories of exemplar cancer – and some other chronic care – programs.

## Cancer Survivorship Service Priorities

Many experts emphasize the importance of the program design process, as well as monitoring, evaluating and refining services. They agree that these programs should use evidence-based approaches, along with clinical and patient input. Five key themes in the recommendations and guidelines for survivorship programs are: i) conducting holistic needs assessments; ii) identifying survivors' unique goals and priorities; iii) developing individualized survivorship care plans; iv) creating tiered or risk-stratified pathways tailored to individual risk profiles and stated needs; and v) ensuring seamless transitions and coordination of care.

An assessment of the impact of the 2006 *From Cancer Patient to Cancer Survivor: Lost in Transition* report ten years later concluded that:

“We must strive to coordinate care, using a risk-stratified approach that not only focuses on cancer-related effects, but also on comorbid medical conditions and socioeconomic disparities. Research should address questions that remain, promote development of measurable outcomes, and evaluate models of care that pertain to real-world decisional dilemmas that are faced by survivors of cancer, their caregivers and clinicians. Health care policy initiatives must fully take on inequities in access and the financial burden of cancer care, and promote strategies to return to work, school, and life. We made progress, but more effort is needed to ensure all survivors receive quality, comprehensive, and coordinated care” (Nekhlyudov, 2017).

The nature of needs assessments and care plans vary greatly across cancer services. Some take a more holistic approach to defining and addressing survivors' needs. However, many do not include a main point of contact, mental health and psychosocial services or return to work support, and risk stratification may be applied formally or informally. The survivorship care plan is meant to support survivors and their health care providers in post-treatment care, including facilitating transition back to primary care. Survivorship plans have varying content, format, timing and mode of delivery. Importantly, many survivors do not receive a survivorship care plan post treatment.

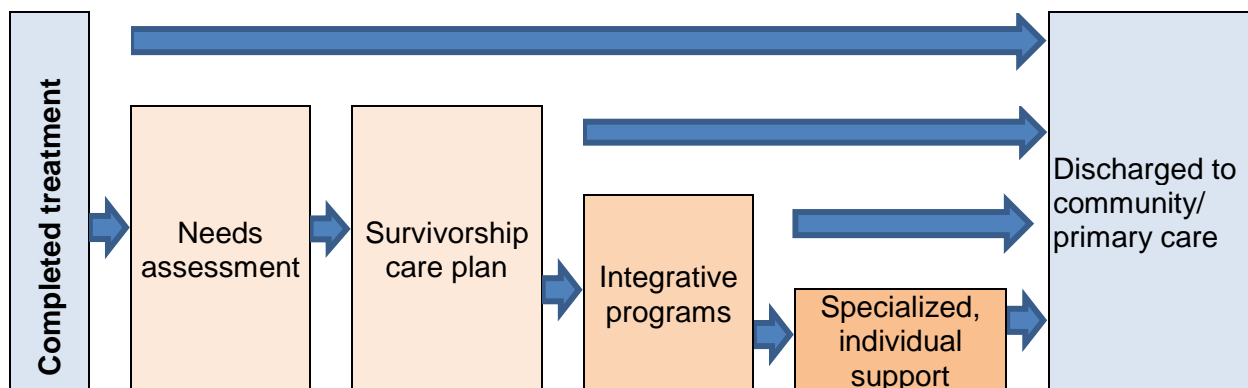
Two approaches to mental health and psychosocial risk assessment include cancer centre-based and universal screening. In the U.S., cancer distress screening and appropriate psychosocial referrals are mandated for cancer centre accreditation. As an example of cancer centre-based screening in Canada, the Psychosocial Oncology division at Princess Margaret Cancer Centre applies the Distress Assessment and Response Tool (DART), a self-assessment used to measure its patients' distress, anxiety, depression and social difficulty. Results go to the patient and into the EMR, and are used by a multidisciplinary team to develop a triaged response plan. Those with low levels of distress are referred to a DART volunteer trained to provide basic information and peer support and to link patients to self-directed resources, such as the Canadian Cancer Society and Wellspring. For those in moderate to high distress, a nurse or oncologist conducts a further assessment and creates a care plan, which could include a range of psychosocial interventions to address their concerns, medication and referral for services, such as home care and spiritual care. In cases where survivors are experiencing high levels of distress, the health care team may refer them to specialized psychosocial oncology services.

The NHS Improving Access to Psychological Therapies (IAPT) program in the U.K. is an example of a more comprehensive universal program. Since 2018, all local health services are required to provide evidence-based treatment for anxiety and depression (according to NICE guidelines) that is integrated with the care pathways for people with long-term physical health conditions and medically unexplained symptoms. The program also includes routine outcome monitoring and support for people finding or staying in work.

## Survivorship Care Pathways

The diagram below outlines the potential psychosocial and mental health care pathways of most cancer survivors. Most are discharged to the community/primary care once their treatment has been completed. Some receive a needs assessment and care plan, which mostly outline a follow-up surveillance plan, and are then discharged. Others, mainly those treated at large cancer centres, may be referred to a variety of integrative programs and services based on their needs and priorities. Those needing specialized psychosocial and mental health may be referred for specialized individual support. While not all survivors want or need psychosocial interventions, many who would benefit from them may not be identified or supported. However, even those offered access to these programs may experience barriers to accessing them due to time limitations, distance, resources and their socioeconomic status.

## Cancer survivor psychosocial and mental health care pathways



Given the diverse needs of cancer survivors, the results of several studies and experts support a multimodal, interprofessional and, in some instances, multi-agency approaches to survivorship programs. Standalone survivorship programs have been found to: have high client satisfaction and experience ratings; result in closer adherence to National Comprehensive Cancer Network (NCCN) and other guidelines; reduce recurrence; increase attendance at various survivorship integrative and supportive services; and show improvement in measures of survivor wellbeing.

### Survivorship Program Models

Multimodal or integrative survivorship programs offer an à la carte selection of services to address physical, mental and psychosocial needs and meet unique preferences and levels of risk. These may be delivered one-on-one, in a group, by telephone or online via videoconferences, webinars, interactive applications and printed information. The following table summarizes the types of services that might be provided by integrative programs. The various multimodal survivorship programs included in this review provide some combination (but not all) of the services outlined.

#### Types of services available at multimodal or integrative survivorship programs

Needs/risk assessment & Survivorship care plan				
Self-help resources	Physical and mental fitness	Educational group sessions	Peer-group support	Individual peer support
<ul style="list-style-type: none"> <li>– Libraries</li> <li>– Online print and video info</li> <li>– Guidebooks, tool kits</li> <li>– Action decks</li> <li>– Interactive guided support</li> <li>– Formal self-management</li> </ul>	<ul style="list-style-type: none"> <li>– Referred to community exercise</li> <li>– On-site time-limited exercise programs</li> <li>– Online exercise program</li> <li>– OT/PY/Kine/SW</li> <li>– Massage/reiki</li> <li>– acupuncture</li> <li>– Specialized rehab program</li> <li>– Neuropsychology</li> </ul>	<ul style="list-style-type: none"> <li>– Diet, nutrition, cooking classes</li> <li>– Medical management and side effects</li> <li>– Yoga, tai chi</li> <li>– Sleep disorders, fatigue</li> <li>– Music/ art therapy</li> <li>– Sexual health and intimacy</li> <li>– Financial/RTW</li> </ul>	<ul style="list-style-type: none"> <li>– Peer group sessions</li> <li>– Topic-based peer support</li> <li>– Online chat groups</li> <li>– Social networking</li> <li>– Group activities, e.g., walking groups</li> </ul>	<ul style="list-style-type: none"> <li>– Peer needs assessments</li> <li>– On-site peer support</li> <li>– Information sharing</li> <li>– Peer buddies</li> <li>– Peer counselling</li> </ul>



Three predominant models of formal survivorship programming emerged from this environmental scan: i) standalone, multimodal survivorship programs within cancer centres, ii) programs and services embedded within the cancer treatment system, and iii) community-based and regional programs.

Examples of cancer centre based survivorship programs include the: Princess Margaret Cancer Centre Cancer Rehabilitation and Survivorship Program; After Cancer Treatment Transition Clinic (ACTT) at Women's College Hospital; National Cancer Institute-designated comprehensive cancer centres in the U.S.; and Sydney Survivorship Centre in Australia. Some centres have dedicated integrative wellness centres onsite. Examples include the: ELLICSR health, wellness and survivorship centre at Princess Margaret; Wellness and Integrated Medicine Center in Buffalo; Leonard P. Zakim Center for Integrative Therapies and Healthy Living in Boston; Integrative Medicine Service in New York; and The Well for Wellbeing Complementary Therapies Centre in Barnsley in the U.K. Several cancer centres also offer targeted services to adult survivors of childhood cancer and adolescent and young adult (AYA) survivors. For example, BC Cancer and BC Children's Hospital offer the Late Effects, Assessment and Follow-up (LEAF) Clinic for young adults or those in middle age who are not in active treatment. St. Jude's Children's Research Hospital in the U.S. offers the After Completion of Therapy (ACT) Clinic, the largest long-term follow-up clinic for childhood cancer patients in the U.S.

With embedded approaches, the patient's cancer care team assesses their post-treatment needs and refers them to treatment and concurrent programs accordingly. At the Odette Cancer Centre at Sunnybrook Health Sciences Centre, patients continue to be seen by their oncology team upon completion of their treatment. The Patient and Family Support Program concurrently offers rehabilitation services, nutritional education, and emotional, social and financial support as part of care before, during and after treatment, including services provided by social workers, psychologists, psychiatrists and occupational therapists. At the Tom Baker Cancer Centre, psychosocial services are integrated into the various cancer departments, with each psychosocial clinician assigned to one or two specific tumour groups. Individual, couple and family counselling are offered by dedicated social workers and psychologists who provide screening, diagnosis and treatment services. Patients may also be referred to psychiatrists. The Australian Cancer Survivorship Centre at the Peter MacCallum Cancer Centre does not provide direct patient care, but works to support and improve the survivorship care provided by the various cancer care streams and departments.

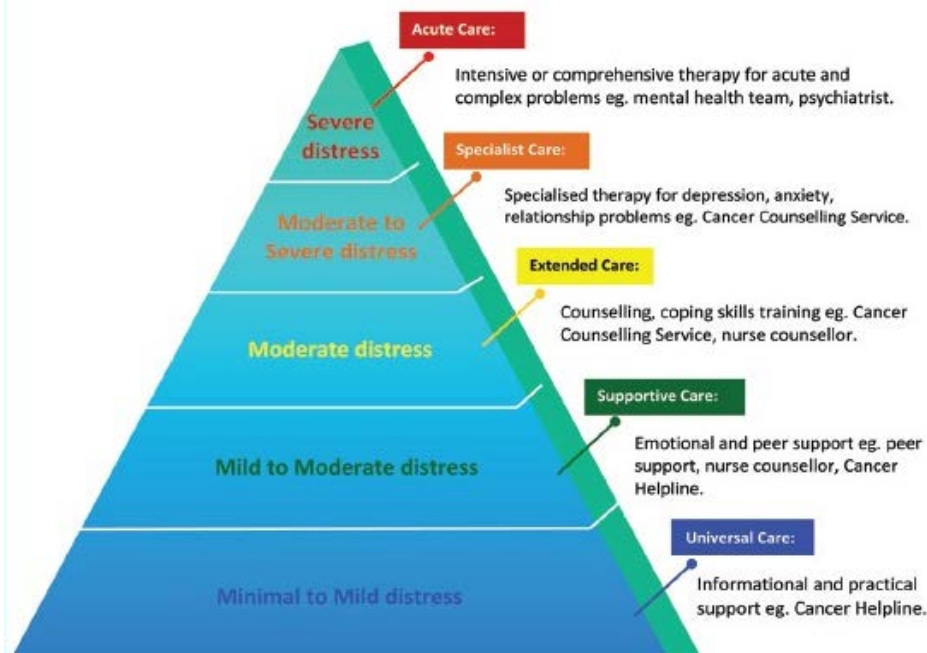
Large not-for-profit organizations provide comprehensive, integrative survivorship programs in several jurisdictions. The Wellspring Cancer Support Foundation is a Canadian example. It offers 35 different programs to meet a wide variety of needs, including peer support, short-term professional counselling, The Healing Journey, Exercise, Relaxation & Visualization, Energy Services, Chi Life, Brain Fog, Nourish, family services, workshops and Be Well Talks, and return to work support.

The Macmillan Cancer Support, Living with and Beyond Cancer Programme provides a single point of contact for accessing services for everyone with a cancer diagnosis within several regions of the U.K. The program includes a Recovery Package – entailing a Holistic Needs Assessment (HNA), a care plan and referrals to the services of many local health and social service partners – and facilitating communication among specialists, primary care providers and patients. The program includes sharable electronic clinical information, allowing various providers to access patients' needs assessments, care plans and treatment summaries. The technology also facilitates remote monitoring, reminders, screening and surveillance close to the home for survivors at stable or low risk. As part of the program, participants are referred to the Improving Access to Psychological Therapies (IAPT) program in their community based on their needs assessment and Recovery Package.

## Levels of Psychosocial Needs

The level of mental health and psychosocial risk and need varies greatly among survivors. The Canadian Association of Psychosocial Oncology has defined a psychosocial distress continuum, and provides stepped-care pathways for cancer-related distress, depression and anxiety.

### Tiered model of psychosocial need and care



(Howell, 2015)

Many survivors with low- to moderate-level psychosocial risk have been shown to benefit from relatively low-intensity peer, group, telephone and web-based interventions – such as the ones identified in the table above outlining the services available at multimodal or integrative survivorship programs – including self-help education, individual and group peer support, group educational sessions and physical activity. Examples of group survivorship educational programs include: Cancer Transitions: Moving Beyond Treatment at the Stronach Regional Cancer Centre; Focus on the Future at the Jewish General Hospital in Montreal; GRACE (Growing Resiliency and Courage) and Emerging from the Haze at Cedars Sinai; and Cancer Transitions: Moving Forward After Treatment at the UNC Lineberger Comprehensive Cancer Center.

## Higher Acuity Mental Health and Psychosocial Services

### Higher Acuity Interventions

Cancer survivors with a higher acuity of mental health and psychosocial require more intensive professionally-led psychosocial interventions. Several cancer centres, and some community-based organizations, offer support by referral to mental health and psychosocial services available within a survivorship program, cancer centre or hospital, or in the community. Providers are generally social workers, psychologists, psychiatrists and nurses. The inclusion criteria and extent of the intervention differs greatly. For example, some programs apply formal screening for distress, others do not. Some programs offer time-limited (three to six sessions) counselling; others provide longer-term support, as required.

Many clinicians and researchers emphasize the importance of integrating psychosocial services into survivorship programs. However, many program representatives reported that psychosocial services

are in high demand in cancer centres and tend to focus on patients during cancer treatment. As such, survivorship programs may develop priorities and care pathways based both on survivors' needs and the availability of resources in the cancer centre, community, primary care and other specialty mental health programs.

The BC Cancer's provincial psychosocial oncology program provides services for patients up to 18 months post treatment. It provides six-sessions of in-person or telephone counselling for patients and their families related to coping with emotions, challenges in relationships and dealing with practical and financial concerns. Wellspring, a community-based organization, provides three, one-on-one counselling sessions to high-need clients. Support includes addressing distress, anxiety and depression, adapting to survivorship, meaning making, addressing past trauma, relationships and attachment, and return to work. As stated above, Improving Access to Psychological Therapies (IAPT) is a universal program that integrates mental health treatment into the care pathways of people with long-term physical health conditions.

As an example from the cardiac care system, the Cardiac Rehabilitation Program at the Ottawa Heart Institute offers access to social workers to assist patients in obtaining medications, applying for financial assistance, ensuring appropriate discharge and return to the community, providing emotional support and counselling to alleviate depression, anxiety and adjustment to their health condition, communicating with family, accessing resources, and providing advocacy and liaison services with other health care professionals and community resources.

Importantly, mental health and psychosocial interventions may need to be tailored to meet the needs of certain population groups. For example, Indigenous cancer survivors could benefit from programs specifically tailored to their individual circumstances, including personalized spiritual care, involvement of family members and elders, and connection to other Indigenous cancer survivors. Nueva Vida, a non-profit organization in the Washington DC area, provides free, comprehensive and culturally competent services to Latinas affected by cancer. Its Mental Health Survivorship program includes bilingual and bicultural psychosocial interventions to support survivors and their caregivers through facilitated, targeted group, and individual therapy.

### **Topic-specific Interventions**

In addition, a number of evidence-based, topic-specific individual and group interventions have proven to be effective in addressing specific cancer-related mental health and psychosocial concerns, including ConquerFear, CALM, The Healing Journey, Stress Management and Resilience Training (SMART) and mindfulness.

ConquerFear is a theory-based metacognition intervention that addresses the way in which individuals think about their thoughts related to fear and worry about cancer recurrence. It entails one-on-one counselling for those with high levels of fear post treatment. Participants receive five 60- to 90-minute sessions with a clinical psychologist or psychiatrist, along with "homework." The Fear of Cancer Recurrence Inventory (FCRI) scale is used to assess the roots of the fear and its severity. The program aims to help people accept and distance themselves from fear and worry, postpone worry, and focus attention where they want it. The approach does not challenge beliefs about the risks of recurrence, but aims to help clients live with uncertainty. The intervention is comprised of screening, values-based goal setting, attention training, detached mindfulness, challenging metacognitions, empowerment to seek information from health professionals, and recognizing signs of recurrence and strategies to avoid relapse.

The Healing Journey Program was developed based on published research and the book by the same name by Alastair Cunningham. The program is offered at Princess Margaret and in the community by Wellspring and Hearth Place Cancer Support Centre, and provides psychological and spiritual tools "to promote inner harmony, peace and healing." The program has been found to reduce anxiety and

depression, restore a sense of control, and relieve symptoms such as fatigue, nausea and pain. The program has six levels. Participants must start at Level 1 and proceed through the levels in order, the latter of which are particularly applicable to survivors. Each level is 10 weeks in length and include:

1. *Coping with Cancer*: relaxation, thought management, visualization, expression of emotions, goal setting
2. *Skills for Healing*: meditation, journaling, spiritual healing, group discussion
3. *Steps Toward Spiritual Healing*: skills to reduce frustration, encourage feelings of peace and equanimity
4. *Becoming Authentic*: explores authenticity, autonomy, acceptance
5. *A New Earth*: studies a book on coping
6. *Healing by Expanding the Sense of Self*: explores potential of the mind to assist in healing physically, mentally, spiritually

Although it is not a survivorship program, Managing Cancer and Living Meaningfully (CALM) addresses tenets of distress that could be applied to survivors experiencing severe distress. CALM is a brief, semi-structured, evidence-based intervention designed for people with metastatic cancer. It focuses on: 1) symptom management and communication with health care providers; 2) changes in self and close relationships; 3) spirituality, sense of meaning and purpose; and 4) sustaining hope and facing mortality. The therapy consists of three to six individual sessions delivered over three to six months by a range of health care professionals.

## Online Interventions

Online services have been shown to address survivors' needs in an accessible, cost-effective and convenient manner. Informational and educational support (e.g., My Journey Kit (Australia) and Cancer Survival Toolbox (U.S.) and social networking (e.g., American Cancer Society's Cancer Survivors Network) are important survivorship resources.

Online mental health and psychosocial counselling support and apps – including cognitive behavioural therapy, lifestyle interventions and symptom management – have been found to be feasible and acceptable to cancer patients, and to be associated with reduced distress and improved coping, self-efficacy and health-related quality of life. However, these programs could benefit from more evidence on best practices and outcomes associated with interventions uniquely for cancer survivors.

Cancer Chat – group therapy provided by psychologists, social workers and nurses – is an example of an online mental health support program in Canada. The eight- to ten-week sessions are topic-specific, including managing insomnia, body image, sexual functioning, fear of recurrence, caregiver support and return to work. Psychosocial intake screening supports appropriate matching of participants and referral to additional services, if warranted. Once started, the groups are closed to additional participants and tailored to meet their needs. As part of therapy sessions, Cancer Chat uses guided imagery, art work, relaxation exercises, self-management tools, thought journals and homework segments. Cancer Chat is also exploring the use of AI to develop an “online co-facilitator.”

Insight is an online rehabilitation program for cancer survivors with persistent cognitive symptoms offered at the Sydney Survivorship Centre and trialled at 18 sites across Australia. Participants receive a 30-minute telephone consultation outlining strategies to address general cognition, memory, concentration and multitasking. They then participate in a 15-week home-based neurocognitive learning program. Based on the neuroplasticity model, it targets cognitive processing systems to improve the speed and accuracy of information processing. It focuses on visual precision, divided attention, working memory, field of view and visual processing speed.

## Primary Care

Primary care plays an important role in the treatment and care of those living with cancer and beyond, and is increasingly being positioned within the cancer care continuum. Several studies have shown cancer patients can safely transition to primary care for follow-up care, with outcomes similar to tertiary care. Family physicians and their patients support a greater role for primary care in follow-up cancer care, but there are several patient, provider and health system barriers to effectively transition survivors to primary care, including the flow of information, coordination and continuity of care, varied guidelines, and the readiness and capacity of primary care. Moreover, according to most experts, access to team-based care within primary care is critical to providing comprehensive post-treatment care. There are examples of initiatives that address capacity in primary care, including Cancer Care Ontario's (CCO) Primary and Community Care Program and the Australian Cancer Survivorship Centre at the Peter MacCallum Cancer Centre.

Survivorship care plans have the potential to play an important role in facilitating transitions from active treatment to primary care. But, their implementation has shown mixed results in terms of improved patient outcomes. These plans vary in content, format, timing and mode of delivery, and some suggest evaluative studies have omitted factors of importance to patients and primary and tertiary providers. As mentioned above, many survivors do not receive such plans.

There is consensus that better integration between primary and tertiary cancer care is required and several integration models, including those related to psychosocial care, could serve as guiding frameworks for improved coordination, continuity and quality of care. These models include the Chronic Care Model, Patient's Medical Home, Primary Care Behavioural Health Model, and Primary Care-Mental Health Integration initiative.

## Return to Work

Employment is a significant concern for many people of working age living with and beyond cancer, and they may experience different work-related physical, cognitive and psychosocial challenges at various stages during and post treatment. Return to work support is important for working-age cancer survivors because it addresses the financial stress and lost income many experience, and because employment has been associated with enhanced overall quality of life in survivors. Several cancer centres and community-based survivorship programs touch on return to work issues and provide education and advice as part of their offerings. For example, return to work may be one of the various topics covered in group educational sessions. Fewer provide dedicated one-on-one or group support in this regard. Examples in Canada include the BC Cancer Vocational Rehabilitation and Wellspring Cancer Support Foundation.

The BC Cancer Agency's Vocational Rehabilitation program provides one-on-one counselling (in-person or via videoconference) by a vocational rehabilitation counsellor and includes case management and referrals. Services include: aptitude, career exploration and return to work readiness assessments; vocational rehabilitation and career counselling; support with graduated return to work; return to school and retraining advice and support; priority setting; maintaining wellbeing and avoiding stress in the workplace; memory and attention adaptation training (MAAT); and understanding and accessing benefits and insurance. Also offered are group seminars on topics such as managing returning to work, job searches, writing a resume and navigating insurance; the "Cancer and Returning to Work" workbook; and online information.

Wellspring provides back to work group workshops and information sessions for people in Toronto, Oakville, Brampton, London, Niagara, Calgary and Edmonton. "Returning to Work" is a six-week group educational and support program led by a specialized social worker. Topics include work readiness, employment accommodations, side-effects that impact job performance, goal setting, and preparation

for the return. The program was previously delivered in-person and still is in Niagara and Calgary, but is now run via videoconference sessions elsewhere. It is accompanied by a workbook outlining session activities and homework. Wellspring also provides two “Back at Work” online videoconference programs once a month that address isolation and how cancer impacts work life, and how stress affects performance and strategies for managing stress at work.

In the “Money Matters” program, a case manager meets one-on-one with those unable to work to assist them navigating income replacement programs, drug coverage and community resources. The program also supports clients with the post-treatment return to work process, including assessing readiness, navigating the disability system, managing paperwork and dealing with insurance companies, employers and government programs related to long-term disability. They are also supported by a five-part video series on “Understanding Long-Term Disability Benefits.” The case worker meets with the client as often as necessary. One-on-one sessions can be face-to-face, online (via Facetime or Skype) or by telephone. As well, participants have access to an employment law clinic that offers one-hour of free advice and a human resources career coach clinic.

Primary care also plays an important role in return to work, including support navigating the insurance system and interacting with employers. The evidence suggests greater knowledge and capacity are needed in this regard. The WSIB Ontario Work Reintegration process provides an example of the key elements of return to work support. As well, there are several online and written supports for return to work, including Cancer and Work in Canada, Cancer + Careers in the U.S. and Work after Cancer in Australia. The “Handbook of Return to Work” – authored by Canadian and American experts – is a synthesis of clinical and occupational interventions to support people in returning to work and sustaining employment after an injury or serious illness.

## Conclusion

Cancer survivors have a variety of physical and psychosocial needs, depending on their individual circumstances. There are many examples of integrative, multimodal cancer survivorship programs in Canada and internationally. These programs vary in their design, structure and program offerings, including the extent of their mental health, psychosocial and return to work services. Survivors at all levels of risk can benefit from an à la carte selection of programs and services to meet their unique needs. Peer support, social networking, educational interventions, and exercise, meditative and recreational programs can all enhance survivors’ mental health and wellbeing. Cancer survivors with a higher acuity of mental health needs may also require more intensive professionally-led psychosocial interventions. As well, return to work support and guidance are an important part of survivorship offerings. Access to integrative programs has shown better client outcomes related to adherence to guidelines, participation in a greater number of supportive services, recurrence and wellbeing. However, the extent of access to these services varies greatly, especially for those not in close proximity to cancer centres or other integrative programs, and for those with limited time, fewer resources and lower socioeconomic status.

Many cancer centres and survivorship programs use the term “discharged to the community.” Discharge may be accompanied with a follow-up plan, referrals to community-based services and coordination with primary care. But, often this is not the case. Primary care plays an important role in the cancer care continuum, including the psychosocial and return to work needs of survivors. However, there are several patient, provider and health system barriers to effectively transition survivors to primary care.

More systematic, universal approaches may result in more survivors getting the supports they need and the psychosocial, mental health-related and return to work programs described in this environmental scan may inform the augmentation of existing programs, along with input from survivors and clinicians.

## **Background**

Many cancer survivors experience psychosocial challenges upon completion of treatment, and many do not receive the requisite treatment and support as they transition back to their daily lives. To address this gap in the continuum of cancer care, the Canadian Partnership Against Cancer commissioned an environmental scan detailing successful Canadian and international mental health and return to work related models of care, programs and services that support working-age cancer survivors to inform its planning and stakeholder engagement to address these issues.

## **Methods**

### **Objective**

The objective of this environmental scan and literature review was to gain input from subject matter experts, summarize the current evidence and create an inventory of effective Canadian and international models of care, programs and services that address working age cancer survivors' mental health, psychosocial and return to work needs.

### **Literature and Program Review**

The literature review entailed thorough searches of national and international published and unpublished literature related to cancer survivorship, with a focus on mental health and return to work and the creation of a customized bibliography. An initial review of existing environmental scans and an exploratory search was conducted to assess the breadth and volume of information available from both the peer-reviewed and grey literature and to inform the development of the search strategy. Thereafter, the review included bibliographical and database searches based on pre-established search parameters and inclusion and exclusion criteria, as well as manual and web-based searches and reviews of grey literature, relevant organizations and networks, and was augmented by references suggested by key informants. Tailored searches commenced with existing literature reviews, systematic reviews and meta-analyses from peer-reviewed sources for an overview of the evidence and to identify key authors, organizations and publications. The searches continued until saturation had been reached. Manual searching of key peer-reviewed journals was also performed. Searches of the grey literature included searches of identified websites, such as governmental, clinical and health organizations, as well as organizations that promote or provide cancer survivorship services.

The results of the literature review and scan of survivorship programs, as well as expert input, were used to develop this report, document case studies and populate an inventory with approximately 140 survivorship programs that address cancer survivors' psychosocial and return to work needs, and another 25 programs related to other chronic conditions (See program lists in Appendices B, C and D).

### **Case Studies and Key Informant Interviews**

Ten key informants with expertise in cancer survivorship were interviewed to provide background and guidance on survivors' needs, service gaps, leading practices, exemplar services and interventions, and other experts in the field to contact. Experts from cancer centres, academic health centres, primary care, and cancer and mental health organizations were included, as well as the editor of the Journal of Cancer Survivorship (Appendix A).

Select cancer survivorship programs in Canada, the U.S., and Australia were identified for further investigation based on the literature review, web scans and key informant interviews. Key informants, with expertise in administering and/or researching successful programs and services for survivors of

cancer and other chronic conditions were interviewed to gather detail on approaches to these services. Representatives were contacted with a request to participate in the scan. Those who consented were sent a questionnaire with open- and closed-ended questions about their program(s). Information gathered included details on service setting, types and content of programs and services, human resources and funding, as well as key success factors and unique aspects of the work. Participants were asked to complete the template prior to a 30 to 45 minute semi-structured telephone interview. For these case studies, detailed information from 19 agencies on 49 programs was documented in an Excel spreadsheet. The results from the questionnaires and interviews are also discussed in this report.

## Findings

### Survivorship Needs

Cancer survivors experience a variety of physical, psychosocial and emotional late or long-term effects of their illness and its treatment, which may depend on the individual, cancer type, stage of diagnosis, treatment regimen and time since treatment ended. As a group, they report poorer health and well-being and relatively higher use of hospital services than those without a previous cancer diagnosis (Richards, 2011). In addition to continued monitoring of their physical health and screening and prevention of recurrence, survivors need a variety of supportive interventions that address their unique needs and concerns, and help them “return to the new normal.”

Distress, fear of cancer recurrence, fatigue, obesity and sedentary lifestyle were the most common symptoms in cancer survivors attending the Sydney Survivorship Clinic (Tan, 2019). In addition to physical problems, recent systematic reviews have found that cognitive limitations, coping issues, fatigue, depression and anxiety affect cancer survivors’ ability to work (Duijts, 2014); and health, relationship and work-related problems can affect their life decisions, quality of life and long-term survival (Schepisi, 2019) (Weinstein, 2018) (Wu, 2015).

A recent national survey conducted by the Canadian Partnership Against Cancer found that most cancer survivors experience mental health challenges upon completion of treatment, and many do not receive requisite treatment and care as they transition back to their daily lives (Canadian Partnership Against Cancer, 2018) (Fitch, 2018). Studies have found that a significant proportion of cancer survivors experience clinically meaningful levels of anxiety and depressive symptoms and reduced mental wellbeing across the cancer trajectory, including post-treatment (Mosher, 2016). Individuals with cancer have significantly higher rates of depressive disorders than the general population (Nakash, 2014) (Smith, 2015) (Krebber, 2014) (Storey, 2019), and youth and young adults tend to be greater risk for depression, anxiety and other conditions than adults with cancer (Park, 2015) (Roland, 2013) (Raphael, 2017) (Mehnert, 2008).

Experts estimate that distress, depression, anxiety and/or cognitive issues occur in 30% to 60% of survivors, with various levels of acuity and support needed. Survivors may experience distress along a continuum, from feelings of vulnerability, sadness and fear to potentially disabling problems, such as depression, anxiety, panic, social isolation and existential spiritual crises. Various sources suggest that between 15% and 40% of survivors have high psychosocial needs requiring support, including fear of recurrence, distress, anxiety, depression and posttraumatic stress disorder (Recklitis, 2017) (Mehnert, 2008), with several studies suggesting that anxiety is more prevalent than depression among long-term cancer survivors and their spouses (Mitchell, 2013). As well, cancer-specific existential distress associated with reduced control, identity, meaning and uncertainty about the future have been found in one in four to five cancer patients (Vehling, 2018). These mental health comorbidities are important considerations for cancer survivors’ quality of life, and because those with mental health conditions have a higher risk of mortality (Ives, 2019) (Zafar, 2019).



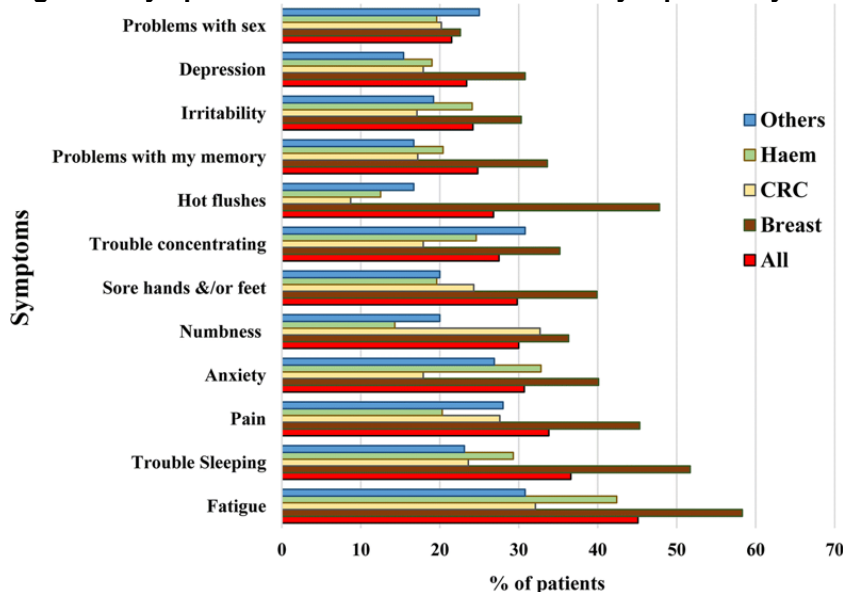
While most studies find improvement over time, others have found time since diagnosis has no significant impact on psychological comorbidity or quality of life (Mehnert, 2008). As well, the type of mental and physical health concerns that may affect mental health can vary by time. For example, those transitioning out of treatment can face immediate challenges returning to their normal social activities or work. Two to five years post-treatment, survivors may experience late-term treatment effects and fear of recurrence. Later, they may develop additional health conditions – given they are at greater risk of acquiring other non-communicable diseases (National Research Council, 2006) (Richards, 2011) – which impact ongoing therapies and their ability to manage follow-up care. At any time, they may experience additional psychosocial and spiritual late-effects stemming from the cancer diagnosis and treatment (National Research Council, 2006) (National Cancer Survivorship Resource Center, 2013).

The needs of cancer survivors have been found to vary by cancer type, gender and age in systematic reviews of the literature. For example, emotional support and reassurance in dealing with fear of cancer recurrence was the most prominent need among people living with and beyond cancer of the colon and/or rectum. Most also had needs related to information/education and health system and patient-clinician communication. Other needs included information about diet/nutrition, self-management of symptoms and complications, fatigue, and on-going contact with health care providers (Kotronoulas, 2017). For ovarian cancer survivors, physical complications and side effects were found to significantly impact their psychosocial health. Access to social support services and relational support were high needs, along with services related to mental health, relationships and sexual function (Roland, 2013). Breast cancer survivors were found to need screening for psychosocial distress, education, social and psychosocial support, and to be better informed about the services available (Mehnert, 2008).

Male survivors of prostate cancer report the following needs in order of frequency: health system/information; interpersonal/ intimacy; psychological emotional; physical; family-related; patient-clinician communication; daily living; practical; spiritual; and social. The most frequently reported unmet supportive needs related to intimacy, informational, physical and psychological needs (Paterson, 2015). For long-term survivors of testicular cancer – the most frequent tumour in young males aged 15 to 39 – physical health, psychological issues, work-related problems, sexual relationships and changing perspectives about work and life were of concern and significantly affected their quality of life (Schepisi, 2019). While many testicular cancer survivors were not found to have significant psychological morbidity, anxiety and fear of cancer recurrence were prevalent. Inadequate coping resources (e.g., low socio-economic status and social support) and strategies (e.g., avoidance) were associated with poorer outcomes (Smith, 2018). For survivors of sarcoma, while improvements in the physical aspects of quality of life were found over time, improvements in psychosocial function or mental health scores were not. This result did not vary by the type of surgery received (Storey, 2019). Esophageal cancer survivors experience significant post-surgical long-term effects that affect their quality of life, including changed eating behaviour, adjusting to a new social identity and high levels of psychological morbidity (Graham, 2016).

In summary, needs and concerns may vary by cancer type, an important consideration for the planning and development of survivorship programs. Figure 1 below summarizes the symptoms of at least moderate severity reported by cancer survivors of colorectal, breast, haematological and other cancers at the Sydney Survivorship Clinic at the Concord Cancer Centre in Australia.

**Figure 1. Symptoms of at least moderate severity reported by cancer survivors**



(Tan, 2019)

Adolescent and youth cancer survivors have been found to have unique needs when they transition out of active cancer treatment, many of which are unmet. Several needs relate to their age and the developmental issues they face. These include identity development, sexual identity, body image, initiating intimate and emotional relationships, separation from parents, fostering autonomy for long-term survivorship, and making independent decisions about future goals such as higher education, career and having a family (Hydeman, 2019) (Barnett, 2016) (Zebrack, 2012) (Ismail, 2018) (Lathren, 2018). Survivors in this age group place a high priority on resuming a normal life, and peer and social isolation are of great concern to them. Personal relationships – including friendships – and those with health care providers are important in helping adolescents and young adults cope with issues related to survivorship. Other support needs identified include cancer-related information, physical activity, relaxation, psychosocial support, nutrition and weight loss. Barriers to accessing support included practical barriers (e.g., limited time), lack of awareness of programs, health issues (e.g., fatigue), and psychosocial barriers (e.g., low motivation) (Rabin, 2010) (Ismail, 2018) (Lathren, 2018).

### Cancer Survivorship Care Priorities and Guidelines

Cancer survivorship is a growing field of inquiry and service development. Survivorship – the late and long-term effects of cancer and its treatment – has increasingly been integrated into cancer care recommendations, guidelines, research and programming. In 2006, the Institute of Medicine (IOM) published *From Cancer Patient to Cancer Survivor: Lost in Transition*, a report with recommendations for enhancing the care of survivors transitioning to life post-treatment (National Research Council, 2006). Subsequently, several jurisdictions have added survivorship to their priorities and guidelines. In the U.S., the National Comprehensive Cancer Network (NCCN) – a not-for-profit alliance of 28 cancer centres that undertake patient care, research and education – has guidelines detailing sequential management decisions and interventions for cancer treatment, including survivorship (Denlinger, 2019). The National Cancer Survivorship Initiative in the U.K. has identified principles and priorities for survivorship care (Edwards, 2019). In 2018, the National Institute of Clinical Excellence (NICE) published new guidance on survivorship care, including a move away from traditional follow-up to an increased focus on supporting holistic needs and developing an individual approach (Edwards, 2019). In March 2019, Cancer Care Ontario published *Follow-up Model of Care for Cancer Survivors: Recommendations for the Delivery of Follow-up Care for Cancer Survivors in Ontario* (Cancer Care Ontario, 2019).

Common documented principles and components of survivorship care include:

- Surveillance, screening and prevention of recurrent and new cancers, as well as physical and psychosocial late effects
- Needs assessments and individualized survivorship care planning based on patient goals and preferences
- Risk-stratified pathways of care
- Self-management information and support with rapid access to referrals and appropriate care
- High-quality, evidence-based care
- Timely and locally accessible services, with alternative modes of care
- Planned transitions and coordination of care among specialists, oncologists and primary care
- Optimal use of health technology (National Research Council, 2006) (Denlinger, 2019) (Glaser, 2010) (Cancer Care Ontario, 2019)

Specifically related to the psychosocial concerns affecting those living with and beyond cancer, the International Psycho-Oncology Society's International Standard of Quality Cancer Care states that psychosocial care should be a universal human right, integrated into routine care and that emotional distress should be measured as the sixth vital sign (International Psycho-oncology Society, 2014). The Canadian Association of Psychosocial Oncology and Canadian Partnership Against Cancer developed Pan-Canadian recommendations and guidance on psychosocial supportive care for adult cancer survivors as follows:

**Table 1. Pan-Canadian recommendations and guidance on psychosocial supportive care for adult cancer survivors**

<p><b>Organization and Care Delivery Structure of Survivorship Services</b></p> <ol style="list-style-type: none"> <li>1. Access to survivorship services that meet a broad range of needs</li> <li>2. Support during the transition to extended survival</li> <li>3. Treatment summary and follow-up care plan</li> <li>4. Care models and coordination of survivorship services, including integration with primary care</li> <li>5. Screening for distress and evidence-based practice</li> <li>6. Active engagement of survivors in self-management</li> <li>7. Survivorship education for health care providers</li> <li>8. Promote awareness of survivorship issues</li> <li>9. Research</li> <li>10. Evaluation of services</li> <li>11. Promote health policy and legislation (employment law, insurance and human rights) to meet survivors' needs</li> </ol>
<p><b>Psychosocial and Supportive Care Interventions</b></p> <ol style="list-style-type: none"> <li>1. Support for healthy lifestyle behaviours</li> <li>2. Use of health-behaviour change, theory-based approaches</li> <li>3. Those with, or at risk of, distress or other psychosocial concerns receive individualized or group-based psychosocial services</li> <li>4. Routine monitoring and management of physiological and psychosocial symptoms, with coordinated shared-care and referrals, as appropriate</li> <li>5. Specific psychoeducation regarding changes in sexual health and function</li> <li>6. Screening for cancer-related fatigue and access to exercise programs combined with psychoeducational interventions and/or multi-component cognitive behavioural therapy</li> <li>7. Survivors with vasomotor symptoms have access to multi-component cognitive behavioural therapy and lifestyle management programs</li> <li>8. Access to multi-component cognitive behavioural therapy programs to manage disruptions in sleep-wake patterns</li> </ol>

(Howell, 2011) (Howell, 2015)

Also of relevance to mental health and return to work concerns of cancer survivors are: the Canadian Association of Nurses in Oncology Survivorship Self-Learning Module (Canadian Association of

Nurses in Oncology 2011); the Mental Health Commission of Canada's Guidelines for Recovery-Oriented Practice (Mental Health Commission of Canada, 2015), Guidelines for the Practice and Training of Peer Support (Sunderland, 2013), and National Standard of Canada for Psychological Health and Safety in the Workplace (Mental Health Commission of Canada, 2013).

Despite increased focus and guidance related to survivorship support and care, unmet needs remain. In a series in *The Lancet Oncology*, Recklitis and Syrjala summarise the existing guidelines and recommendations for providing routine psychosocial care to cancer survivors, describe challenges in providing this care, and make recommendations for improved integration of psychosocial services into survivorship care (Recklitis, 2017). An assessment of the impact of the 2006 IOM report ten years later found that, while progress had been made, many survivors were still "lost in transition" and:

"We must strive to coordinate care, using a risk-stratified approach that not only focuses on cancer-related effects, but also on comorbid medical conditions and socioeconomic disparities. Research should address questions that remain, promote development of measurable outcomes, and evaluate models of care that pertain to real-world decisional dilemmas that are faced by survivors of cancer, their caregivers and clinicians. Health care policy initiatives must fully take on inequities in access and the financial burden of cancer care, and promote strategies to return to work, school, and life. We made progress, but more effort is needed to ensure all survivors receive quality, comprehensive, and coordinated care" (Nekhlyudov, 2017).

## Program Design

### Program Development

Experts highlight the importance of the process employed in designing and implementing survivorship programs, as well as monitoring, evaluating and refining them. They agree that these programs should be developed and implemented using evidence-based approaches to define the parameters of survivorship care and delivery models, and to tailor them to meet the needs of various cancer survivor populations. While the studies cited above and others identify many of the supportive needs of cancer survivors, several authors suggest that more theory-driven research is required to assess the mental health and wellbeing needs of survivors and define individual and external risk and protective factors in order to determine appropriate programming and interventions. They also report that gaps remain in the understanding of the various trajectories among individuals and the evolution of their needs and outcomes over time (Mosher, 2016) (Smith, 2018) (Paterson, 2015) (Storey, 2019) (Raphael, 2017).

Program design considerations should include client needs assessments, client input on their needs and desired program components, optimal modes of service delivery, optimal timeframes for transitioning patients to survivorship care, gaps in existing programs, and barriers to access (Glaser, 2019) (Hydeman, 2019) (National Cancer Survivorship Resource Center, 2013). As an example, the Bronx Oncology Living Daily (BOLD) program was developed based on psychosocial needs assessments to determine which services would best help clients cope and take charge of their health. More than half wanted mind-body programs, physical fitness and nutrition workshops, creative arts programs, and health education classes, and one-quarter requested individual counselling, telephone support and someone to accompany them to treatment. These stated needs are reflected in the BOLD program offerings.

Some key requisites identified for developing integrative survivorship programs are institutional support, strong leadership, a clear vision of how the program will function, a dedicated team and clinical oncology champions to refer patients in the program. The inclusion of survivorship plans, needs assessment screening and tailored programs have also been identified as critical program components (Glaser, 2019). Choice, flexibility, convenience and commonalities with other program participants are reported by participants to be important considerations in program design (Rabin,

2010). Advertising and getting the word out about available programs is also important to their success, and for some centres is an ongoing challenge. Several organizations report that continual program promotion and reaching out to other departments that treat and interact with cancer patients is critical to reaching clients and generating referrals.

Many organizations have formal processes for program development. For example, Wellspring Cancer Support Foundation reports that it follows these steps. It: 1) identifies a gap in its services; 2) conducts and reviews the research; 3) develops a proposal; 4) submits it to a program review committee of social workers, psychologists, patients and researchers for assessment; 5) pilots and evaluates the accepted programs for six to 12 months; 6) submits the evaluation results to the program committee; 7) adjusts the program based on the evaluation and committee's input; and 8) implements the program, along with an ongoing monitoring and evaluation plan.

The Macmillan Living with and Beyond Cancer Programme serves a population of 2.5 million in Barnsley, Bassetlaw, Doncaster, Hardwick, North Derbyshire, Rotherham, Sheffield and Wakefield. The program was developed based on evaluations of earlier projects and pilots, best practices in the U.K. and internationally, and guidance from the National Cancer Task Force Strategy. A proposal was developed for the entire service area that outlined the program goals, content and anticipated outcomes. Macmillan then spent a year engaging with steering groups and patient advisors in each jurisdiction to design a local implementation plan that reflected the local context and needs. Each locale had different types of services and providers available, including the local volunteer and charity sectors. Thus, in each they identified existing programs and services that could support those living with cancer and beyond, as well as the gaps, and worked with various agencies to develop an integrated service plan that provides access to a single point of service contact and complements the clinical oncology treatments and care. In each region, the program devised ways to link with hospital-based cancer clinics, health and social services, primary care and community-based services, and support patients at any point in their cancer journey based on a needs assessment and individualized care plan. A common theme in each locale was that program participants prefer to access supportive services locally, including generic supportive services “without a cancer label.” Implementation is at different stages across the eight regions, with one in operations for two and a half years and another currently introducing the services.

### Key Program Design Features

Two key themes in the various survivorship recommendations and guidelines are survivorship care planning and risk-stratified pathways of care. The Institute of Medicine's 2006 “Lost in Transition” report and subsequent guidelines have recommended the creation of individualized survivorship care plans upon completion of treatment, summarizing cancer treatments, current health status and follow-up care recommendations based on their personal circumstances. The care plan is meant to support survivors and their providers in post-treatment care, including facilitating transition back to their primary care provider (National Research Council, 2006). Many survivorship programs now offer stratified pathways of care post treatment based on a personal care plan. The National Cancer Survivorship Initiative model is unique in that it initiates care planning at diagnosis and updates it as required post treatment. A review of survivorship care plans in Canada, the United States, Europe, the United Kingdom, Australia, and New Zealand found that the plans incorporated several of the IOM's guidelines, but varied significantly in their content. Many did not include a key point of contact, psychosocial services, and financial/return to work (Daudt, 2014).

Many experts recommend the use of one or more functional, psychosocial and health-related quality of life screening (and evaluation) tools – such as those listed in Table 2 – be administered in conjunction with the development of the post-treatment survivorship care plan and periodically thereafter (Dietrich, 2016) (Glaser, 2019) (Cheng, 2017) (Glaser, 2019) (Recklitis, 2017). Notably, some suggest that some of the psychological screening approaches being used have “not been validated against gold-standard psychiatric-structured interviews in cancer survivors” (Recklitis, 2017).

**Table 2. Psychosocial measurement tools**

BDI – Beck Depression Inventory	FRI – Family Relationship Index
BIAQ – Body Image Avoidant Questionnaire	FSI – Fatigue Symptom Inventory
BIQ – Body Image Questionnaire	FCRI – Fear of Cancer Recurrence Inventory
BIS – Body Image Scale	FSFI – Female Sexual Function Index
BFI – Brief Fatigue Inventory	HADS – Hospital Anxiety and Depression Scale
BPI – Brief Pain Inventory	HR-QOL- Health-Related Quality of Life
CCAT-PF – Cancer Communication Assessment Tool for Patients and Families	IES-R – Impact of Events Scale - Revised
CARES-SF Sexual subscale – Cancer Rehabilitation Evaluation System-Short Form	LASAS - Linear Analog Self-Assessment Scale
CASE-C – Communication and Attitudinal Self-Efficacy Scale-Cancer	MPQ – McGill Pain Questionnaire
CARS – Concerns About Recurrence Scale	MOS SPSI – Medical Outcomes Study Sexual Problems Survey Instrument
CBA-OE – Cognitive Behavioural Assessment for Outcome Evaluation	MOS SSS – Medical Outcomes Study Social Support Survey
DDRS – Connor Davidson Resilience Scale	MSPSS – Multidimensional Scale of Perceived Social Support
CES-D – Center for Epidemiologic Studies-Depression 10	MYCaW – Measure Yourself Concerns and Wellbeing
DART - Distress Assessment and Response Tool	PAM – Patient Activation Measure
DAS – Dyadic Adjustment Scale	PRCI – Partner Response to Cancer Inventory
DCI – Dyadic Coping Inventory	PREM – Bespoke Patient Reported Experience Measure
DUREL – Duke University Religion Index	PHQ-9 – Patient Health Questionnaire
ESAS-AL – Edmonton Symptom Assessment System	PSCC – Patient Satisfaction with Cancer-Related Care
ENRICH – Enriching & Nurturing Relationship Issues, Communication and Happiness	PHCS – Perceived Health Competence Scale
EORTC-QOL-30 European Organization for the Research and Treatment of Cancer, Quality of Life	PSS – Perceived Stress Scale
FACIT – Functional Assessment of Chronic Illness Therapy	PTGI – Post-traumatic Growth Inventory
FACT - Functional Assessment of Cancer Therapy	PCDSCS – Primary Care Delivery of Survivorship Care Scale
FACES II – Family Adaptability and Cohesion Evaluation Scales	POMS-SF Anxiety, Depression and Fatigue subscales – Profile of Mood State-Short Form
F-COPES – Family Crisis Oriented Personal Evaluation Scales	QOL-CS Quality of Life-Cancer Survivors
FES – Family Environment Scale	SAS – Smith Anxiety Scale
FSS – Family Satisfaction Scale	SEMCDs – Self-Efficacy for Managing Chronic Disease Scale
	STAI – State-Trait Anxiety Inventory
	SCE – Survivorship Care Expectations
	SBI-15R – Systems of Belief Inventory
	SF36 - 36-Item Short Form Survey

(Dietrich, 2016) (Glaser, 2019) (Cheng, 2017) (National Cancer Survivorship Resource Center, 2013) (Seers, 2018) (Polley, 2016) (Cipolletta, 2019) (Loprinzi, 2011) (Saracino, 2019).

Several survivorship programs have formal and informal risk-stratified care pathways. At the first level, it is not uncommon for survivors to be referred “back to the community” upon completion of treatment without a care plan; they are monitored for physical symptoms by their oncologist and primary care providers at predetermined intervals and can access various services in the community based on self-referral and provider recommendations. For those who receive a survivorship care plan, the plan includes a surveillance schedule, recommendations for self-management and supportive programs, and for those at higher-risk, referral to tailored rehabilitation and supportive programs.

As an example, the U.K. National Cancer Survivorship Initiative tiered model for care planning is shown in Figure 2 below. The model stratifies survivors’ follow-up activities based on their capacity to self-manage (Daudt, 2014) (National Health Service (UK), 2011), with the premise that survivors should be encouraged to self-manage with adequate information and support and have rapid access to appropriate professionals should problems arise. The Information survivors receive should meet their individual needs, be timely and accessible, and promote confidence, choice and control. There is also an emphasis on leveraging technology to better meet individual needs. Planned, coordinated care in the clinic, community or via telephone and internet is recommended for those who are unable to self-manage, and multidisciplinary case management is applied to those with complex complications, symptomatic needs or rapidly changing health (Glaser, 2010).

**Figure 2. National Cancer Survivorship Initiative Stratified Model of Care**



**Risk Stratified Model of Care**

(Glaser, 2010)

The Macmillan Living with and Beyond Cancer Programme, offered in eight regions of the U.K., applies the stratified follow-up pathways. Informed by both a clinical and holistic perspective, pathways were developed for each tumour group by multidisciplinary team leads, cancer nurse specialists, representatives from radiology and pathology, commissioners and primary care. The aim was to match the level of support based on individuals’ holistic and clinical needs, including the likelihood of treatment related side effects and risk of recurrence. Patients assessed to be stable or low risk have relatively more supported self-management and remote monitoring, which includes locally-based surveillance and testing, saving them a trip to the hospital which may be in another jurisdiction. The following outlines the stratification guidelines for breast cancer.

**Table 3. Living with and Beyond Cancer Programme stratification guidelines for breast cancer**

<p>“Breast stratified follow-up guidelines were well established across the Alliance’s geography. The team reviewed and agreed [on] refreshed guidelines in March 2018. Two patient cohorts were identified: low-risk and high-risk.</p> <p>Early on in the pathway, it is explained to all patients that follow-up is a five year process combining clinical input and surveillance. Low-risk patients, assessed as low clinical risk with a lower degree of psycho-social need, are more likely to be followed-up in clinic for one year before moving onto supported self-management. For five years, they will also have routine annual mammograms, organised through an electronic system. High-risk patients, assessed as having either higher clinical risk and/or a higher degree of psychosocial need, also have access to a five year follow up process combining clinical input and surveillance, however this group of patients have more regular face-to-face contact over the five years.</p> <p>CNSs [cancer nurse specialists] and cancer support workers (CSWs) provide support to patients before they move onto self-management through the Recovery Package interventions, designed to deliver a person-centred approach to care. This includes a holistic needs assessment (HNA) and care planning process. In some trusts, CSWs support the HNA, as well as providing information and support. Outside an acute hospital setting, patients have conversations about their needs with experienced care navigators, social prescribers, support workers or volunteers based in a range of organisations. Patients also have access to a range of courses, such as the Breast Cancer Care Moving Forward course and the Macmillan Hope course” (Metcalf, 2018).</p>
--

## Funding

In Canada, Australia and the U.K., survivorship services provided in cancer centres are publicly-funded. In the U.S., there are cancer centres with survivorship programs in public, private and not-for-profit hospitals. The various international community-based organizations that provide in-person and/or online services to survivors generally receive money through corporate and private donations, community partners and some earmarked government funding. Ongoing funding is required to ensure sustainability.

In Canada, Australia and the U.K., almost all survivorship services provided by publicly-funded institutions and community-based organizations and charities are free of charge. In some cases, there may be a small fee or a limited number of sessions for particular programs, such as physical and exercise-related activities. Importantly, however, community-based rehabilitation (e.g., physiotherapy and occupational therapy) and psychological services (e.g., psychology) are not covered by Medicare in most Canadian jurisdictions. In the U.S., patients may claim for clinical interventions related to survivorship through their insurance or pay out-of-pocket. Several of the activities and programs provided through large hospital-based survivorship centres are offered free of charge.

## Program Monitoring and Improvement

Monitoring and evaluation are important components of program design and implementation. They are required to identify service gaps, measure quality and effectiveness, and ensure services continue to reach and meet client needs (Kotronoulas, 2017) (Dietrich, 2016) (National Cancer Survivorship Resource Center, 2013). Many programs undertake informal evaluations of client satisfaction and experience, usually by survey, and in some cases, key informant interviews and focus groups. Some programs use an informal plan-do-study-act approach to program assessment. While many organizations conduct pre-post program evaluations via participant surveys, fewer conduct formal evaluations of particular programs within their service offerings, and even fewer evaluate their program in its entirety.

Many cancer centres, such as Princess Margaret and Tom Baker Cancer Centres in Canada, Memorial Sloan Kettering in New York, Dana-Farber in Boston and Roswell Park in Buffalo are co-located with research centres. Several, such as Princess Margaret, collaborate with in-house and external research institutes. Some community organizations, such as Wellspring, also participate in research. Some programs suggest specific approaches and measures for research and evaluation. The Tom Baker Cancer Centre reports that translating research into clinical practice and enabling clinical knowledge and expertise to inform research are central to the success of its program. There is an explicit focus on identifying service gaps and patient needs and developing interventions and programming to address these gaps and supplement core clinical operations. As well, the Department of Psychosocial Oncology's training program contributes significantly to clinical research. The National Cancer Survivorship Resource Center in the U.S. recommends that evaluations should include assessments of the effectiveness of program promotion and reach for the potential client population, barriers to access and client experience and satisfaction. Impact and outcomes should be assessed over the short-, medium and long-term, including changes in participant knowledge, behaviours, functional status, coping and self-management skills, quality of life, and morbidity and mortality (National Cancer Survivorship Resource Center, 2013). The Living With and Beyond Cancer Programme supported by Macmillan Cancer Support in the U.K. has a robust evaluation framework and plan to assess: client, health care provider and health care system outcomes; differential benefits and outcomes; individual, program design and locality predictors of outcomes; and program sustainability and scalability. Researchers stress the importance of using reliable and validated tools and repeated outcome measures to assess outcomes. Possible measurement tools are included in Table 3 above.



## Survivorship Program Models

Given the diverse needs of cancer survivors, several studies and experts promote a multimodal, multi-professional and, in some instances, multi-agency approaches to cancer survivorship programs (Kotronoulas, 2017) (Hydeman, 2019) (Glaser, 2019) (Tan, 2019). The U.S. National Cancer Survivorship Resource Center defines a survivorship program as having the:

"goal to maximize the quality of life of survivors and their caregivers. The program should include a comprehensive set of services provided by multidisciplinary groups working together to assure effective medical care, education and emotional support. Communication between and among survivors, their caregivers and providers is essential for the seamless referral, navigation and coordination of these services" (National Cancer Survivorship Resource Center, 2013).

Three predominant models of formal survivorship programming emerged from the literature and environmental scan. These included standalone multimodal programs within cancer centres, programs and services embedded within the cancer treatment system, and community-based and regional programs.

### Standalone Multimodal Programs within Cancer Centres

Many of the cancer centres included in this review offer comprehensive, multimodal, integrative survivorship programs. In research studies, several of these programs have been found to: have high client satisfaction and experience ratings; result in closer adherence to National Comprehensive Cancer Network (NCCN) and other guidelines related to survivorship; reduce recurrence; increase the frequency with which attendees attend other survivorship integrative and supportive services; and show improvement in measures of survivor wellbeing (Dietrich, 2016) (Tan, 2019) (Seers, 2018) (Glaser, 2019).

Examples of cancer centre based survivorship programs include the: Princess Margaret Cancer Centre Cancer Rehabilitation and Survivorship Program; After Cancer Treatment Transition Clinic (ACTT) at Women's College Hospital; National Cancer Institute-designated comprehensive cancer centres in the U.S.; and Sydney Survivorship Centre in Australia. These dedicated clinics generally include an initial assessment, review of the medical history, advice on living healthily, and the development of a tailored survivorship care plan by a nurse practitioner or physician assistant, sometimes supported by rehabilitation and other professionals. The care plans are used to guide ongoing surveillance, clinical decision making and referrals to supportive care services. Visits can be a one-time consultative visit or entail regular follow-up.

Survivorship clinics are generally complemented and supported by other programs and services to which clients can be referred. These usually include mental health counselling, diet and nutrition education, sexual health and fertility support, and access to complementary or "integrative" therapies such as exercise, massage, acupuncture, meditation, tai chi and yoga. Some centres have dedicated integrative wellness centres onsite. Examples include the: ELLICSR health, wellness and survivorship centre at Princess Margaret; Wellness and Integrated Medicine Center in Buffalo; Leonard P. Zakim Center for Integrative Therapies and Healthy Living in Boston; Integrative Medicine Service in New York; and The Well for Wellbeing Complementary Therapies Centre in Barnsley in the U.K.

There are also several cancer centres that offer targeted services to adult survivors of childhood cancer and adolescent and young adult (AYA) survivors. For example, the BC Cancer Agency and BC Children's Hospital offer the Late Effects, Assessment and Follow-up (LEAF) Clinic for young adults or those in middle age who are not in active treatment. St. Jude's Children's Research Hospital in the U.S. offers the After Completion of Therapy (ACT) Clinic, the largest long-term follow-up clinic for childhood cancer patients in the U.S. Other examples of standalone long-term follow-up and AYA

survivor programs are those offered at the Moffitt Cancer Survivorship Clinic in Florida, Memorial Sloan Kettering Cancer Centre in New York, Dana-Farber Cancer Institute in Boston, Roswell Park Comprehensive Cancer Centre in Buffalo, and Simms/Mann UCLA Center for Integrative Oncology at UCLA.

### **Embedded Services**

While many cancer centres offer standalone survivorship centres, several integrate survivorship services into the various oncology departments. The Australian Cancer Survivorship Centre at the Peter MacCallum Cancer Centre does not provide direct patient care, but works to support and improve the survivorship care provided by the various cancer care streams and departments. The centre's work includes developing and promoting the use of survivor care plans, fostering and promoting support strategies and models (e.g., for sleep deprivation and fear of recurrence), supporting providers in the cancer streams in designing and delivering survivorship services, promoting routine screening for distress, promoting psychosocial oncology referrals, and identifying resources in the community. The centre also works to improve access to requisite information and resources post treatment, including audio and video information and information in languages other than English.

Roswell Park Comprehensive Cancer Centre in Buffalo has a standalone Survivorship Clinic, but during its planning, oncologists requested that the decision to access the survivorship program was that of the oncology care team. Thus, Roswell Park developed a mixed model where some departments would refer patients to the centralized survivorship program, whereas others would provide these services within the oncology practices. The survivorship clinic is also available to support the practices in developing a survivorship care pathway and potentially determining the optimal time for transitioning patients to the survivorship service, to ensure patients feel comfortable and supported through the transition. Access to the survivorship clinic is also available through self-referral (Glaser, 2019).

At the Odette Cancer Centre at Sunnybrook Health Sciences Centre, patients continue to be seen by their oncology team upon completion of their treatment. The Patient and Family Support Program concurrently offers rehabilitation services, nutritional education, and emotional, social and financial support as part of care before, during and after treatment, including services provided by social workers, psychologists, psychiatrists and occupational therapists. At the Tom Baker Cancer Centre psychosocial services are integrated into the various departments, with each psychosocial clinician assigned to one or two specific tumour groups. Many of the clinical interventions are tailored to the unique needs associated with a specific type of cancer. This approach is applied to enhance tumour site specific knowledge and skills, integration with multidisciplinary tumour teams, and the incorporation of clinical research. Patients are self-referred or provider-referred for individual, couple and family counselling by dedicated social workers and psychologists who provide screening, diagnosis and treatment services. Patients may also be referred to psychiatrists. As of 2019, AYAs and Indigenous cancer patients have specialized nurse navigation services.

### **Community-Based and Regional Programs**

There are several community- and regionally-based survivorship programs that offer multifaceted, integrative services. Some studies report that this is a safe and effective approach to post-treatment follow-up care (Edwards, 2019). For example, the Wellspring Cancer Support Foundation offers 35 different programs to meet a wide variety of survivorship needs, including peer support, short-term professional counselling, The Healing Journey, Exercise, Relaxation & Visualization, Energy Services, Chi Life, Brain Fog, Nourish, family services, workshops and Be Well Talks, and return to work support.

Macmillan Cancer Support provides leadership, coordination, funding and evaluation support for the Living with and Beyond Cancer Programme in partnership with the National Health Services (NHS) in South and Mid Yorkshire, North Derbyshire and Bassetlaw. The program is delivered locally with a single point of contact for accessing services. Participant services and providers differ across localities, but generally include NHS providers (hospitals, community services and primary care), Macmillan staff, Age UK, independent providers, community services and local charities. The program first focused on breast, colorectal and prostate cancer and is planning implementation for all people affected by cancer. A “Recovery Package” is offered to all patients, with a focus on personalised support and care, starting with the Holistic Needs Assessment (HNA) and a care plan that guide linkages and referrals to education and support in the community based on expressed needs. In addition to the HNA and care plan, the Recovery Package includes: 1) a treatment summary to facilitate communication between secondary and primary care; and 2) a cancer care review to support conversations in primary care with a family physician or practice nurse. The program is characterized by its sharable electronic clinical information. A web-based system allows provider access to patients’ needs assessments, care plans and treatment summaries. Patient completed information (online or via a tablet) is uploaded to the system. The technology also facilitates remote monitoring, reminders, screening and surveillance close to the home for survivors at stable or low risk, and population-based planning and research.

As discussed above, the program includes risk stratification to determine the most appropriate follow-up pathways for aftercare services based on individual clinical and holistic needs. “Supported Self-management” assists clients in understanding and managing any consequences of treatment, pursuing healthy lifestyles and wellbeing, and accessing other support and services. Clients are informed about or referred to various programs in their community that meet their needs. Some are specifically cancer-related, others are more generic. In Sheffield – with a population of about half a million – the program partners with approximately 300 small- and medium-sized voluntary and charitable organizations which provide a range of services, including psychosocial counselling, support groups and workshops, self-management support, nutrition advice, complementary therapies, exercise, and meditation.

The Living with and Beyond Cancer Programme is offered based on an “opt out” basis, whereby every cancer patient is offered a HNA/care plan and support, and it is their choice whether to accept or decline. An estimated 80% of those newly diagnosed with breast, colorectal or prostate cancer are accessing support where the program is offered. In one community, 90% of those diagnosed are in the program, with 300 people having been referred to 900 services in their area.

Penny Brohn is a U.K. charity and its program takes an integrative (whole person) approach to providing physical, emotional, psychological and spiritual support to patients at all stages of cancer. For survivors, it offers courses, groups and individual sessions on how to eat well, stay active, manage emotions and relationships, and reconnect with life. Penny Brohn evaluated its Living with and Beyond Cancer classes and participants reported statistically significant improvements in their lifestyle, ability to self-manage, main cancer-related concern, wellbeing and patient activation (Seers, 2018). Spiritual, emotional and functional wellbeing improvements were found at 12 months at the National Centre (Polley, 2016).

Also of relevance to cancer survivorship is the multifaceted U.K.-wide Stroke Association’s Life After Stroke Services. The National Stroke Strategy states that all survivors are entitled to a review of their needs at six months. To meet these requirements, Life After Stroke Services include: Post-Stroke Reviews, Moving Forward After Stroke, Communication Support Service, Emotional Support Service, and Caring and You. The Post-Stroke Review is performed by a stroke recovery coordinator who identifies survivors’ needs and provides informational and service referral advice. The needs assessment covers 35 common problem areas related to their health, medical, social and emotional needs. The results and a recovery plan are shared with the client and primary care team, and

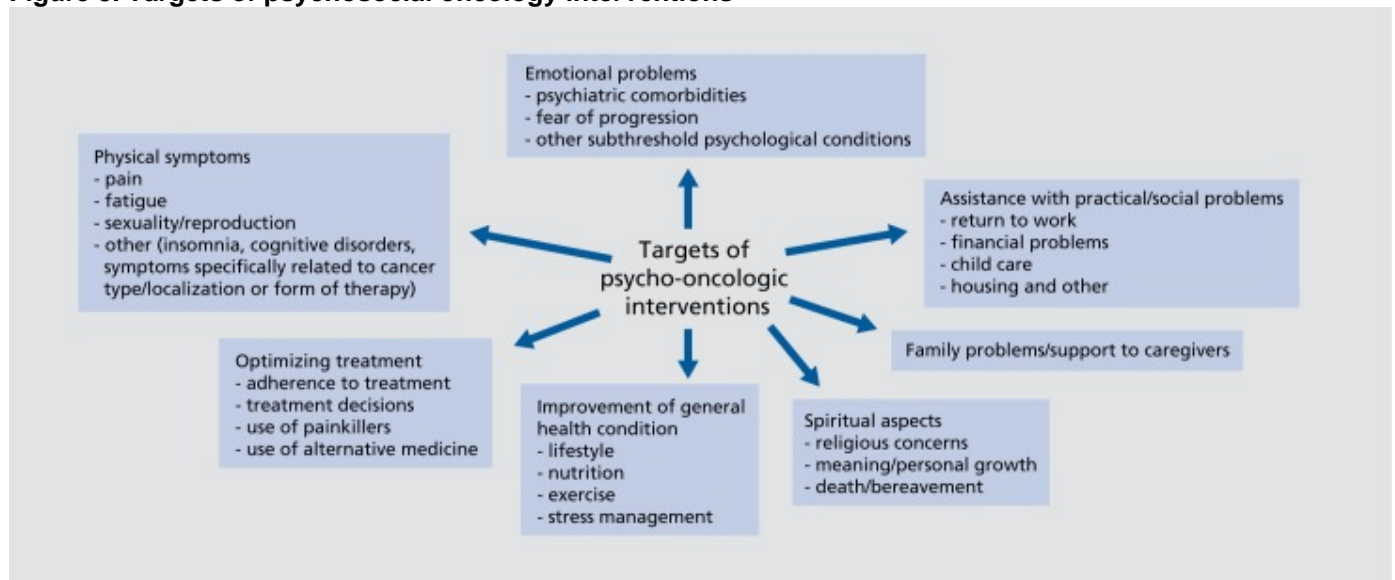
participants are referred accordingly. The Emotional Support Service provides counselling to stroke survivors and caregivers requiring specialist support at Level 3 of the National Institute for Health and Care Excellence (NICE) four-tier model of psychological support. Professional counsellors address issues such as loss and adjustment, relationships, guilt and anger, and building confidence and self-esteem. The service also offers peer support sessions run by trained volunteers and supported by the Emotional Support Coordinators. The Moving Forward After Stroke program is a 12-week exercise and education program open to survivors at any stage. The Communication Support Service helps survivors with a language disorder relearn communication skills. The Caring and You program provides support and education to family or friends of survivors. The program has been found to increase knowledge, confidence, physical wellbeing and communication skills, and reduce anxiety, emotional distress, isolation, risk factors and caregiver stress (Stroke Association, 2018) (Wright, 2016).

## Psychosocial Services

### Service Targets and Stratification

Psychosocial services are a critical component of survivorship programs. As discussed above and shown in Figure 3 below, the psychosocial needs of cancer survivors can vary in nature, complexity, severity and time since the end of treatment. While not all survivors want or need psychosocial interventions, many who would benefit from them may not be identified or supported. The evidence suggests that some early interventions can mitigate adverse mental health outcomes resulting from surviving life-threatening medical events (Birk, 2019) (Levin, 2015) (Willems, 2017). In the U.S., cancer distress screening and appropriate psychosocial referrals are mandated for cancer centre accreditation.

**Figure 3. Targets of psychosocial oncology interventions**

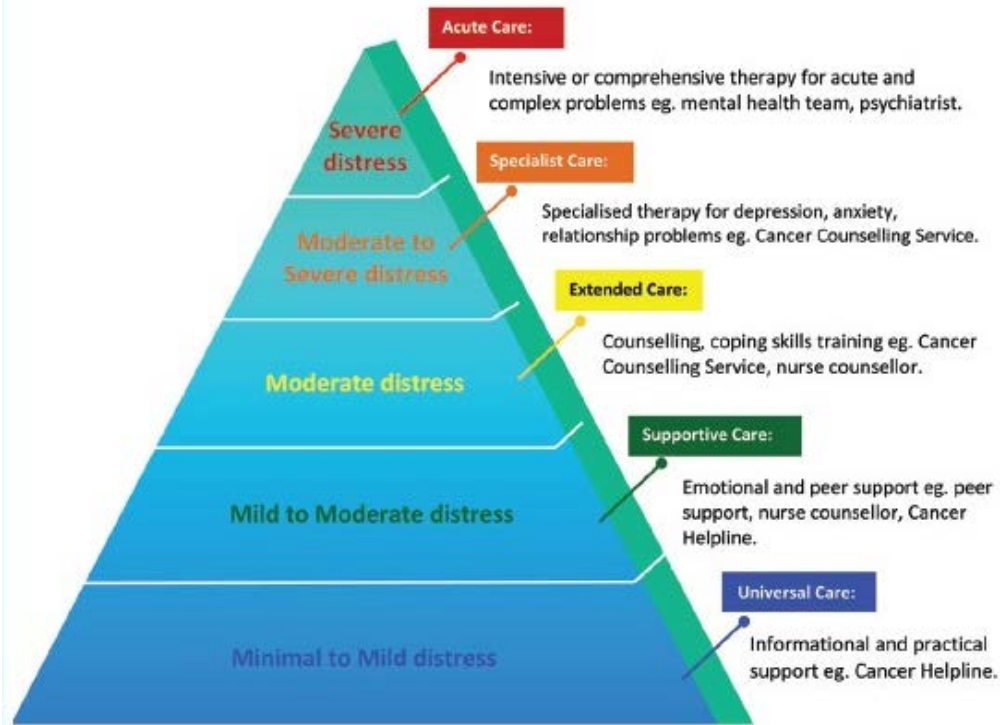


(Lang-Rollin, 2018)

Many clinicians and researchers emphasize the importance of integrating psychosocial services into survivorship programs (Recklitis, 2017). However, many program representatives report that psychosocial services are in high demand in cancer centres and tend to be focused on patients during cancer treatment. As such, survivorship programs tend to develop priorities and care pathways based both on survivors' needs and the availability of resources in the community, primary care and specialty mental health programs.

The Canadian Association of Psychosocial Oncology defines the psychosocial distress continuum and provides stepped care pathways for cancer related distress, depression and anxiety in adults with cancer. Figure 4 shows its tiered model of psychosocial care (Howell, 2015). Acknowledging that survivors' psychosocial needs differ from those in active treatment and by individual, whether by design or default, cancer centres and some community agencies, such as Wellspring and Macmillan, apply a stratified risk model for meeting psychosocial needs.

**Figure 4. Tiered model of psychosocial need and care**



### Low Risk

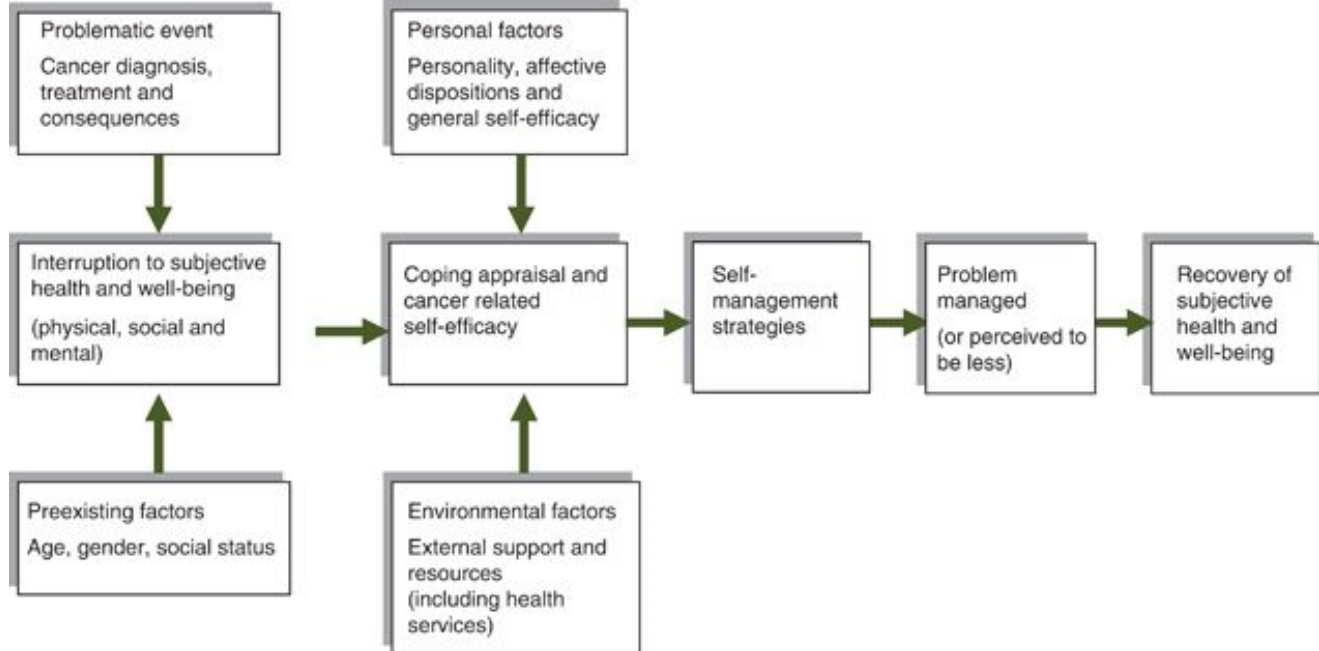
Many survivors, deemed to be at a low level of psychosocial risk, have been shown to benefit from relatively low-intensity group, home-based, telephone and web-based interventions, including self-help education, individual and group peer support, group educational sessions and physical activity.

### Self-Management

Cancer survivors use a range of strategies and resources to self-manage, which may include family, friends, health care providers, health services, community agencies, colleagues, the Internet, etc. Self-management programs, such as the Expert Patient Program developed at Stanford University, provide a generic set of skills to help people self-manage their long-term health conditions. A critical part of self-management through transitions is said to be giving people the tools to “restore order in their disrupted lives.” Such programs have been found improve self-efficacy, health status and quality of life and reduce health service utilization (Foster, 2011). Systematic reviews have shown that supported self-management programs can help with the development of self-regulatory health behaviours and management of the biopsychosocial impacts of several chronic conditions, and improve health outcomes (Howell, 2018).

Figure 5 provides a conceptual framework for cancer self-management and puts an emphasis on self-confidence and self-efficacy for recovery (Foster, 2011). However, some research suggests that a generic approach for chronic disease self-management may not be sufficient for complex chronic illnesses like cancer, and such programs may need to be tailored to cancer survivors (Howell, 2018).

**Figure 5. Conceptual framework for cancer self-management**



(Foster, 2011)

The Cancer Thriving and Surviving Self-Management Program in British Columbia is a licensed program developed at Stanford University. It follows a standardized format and is available to adults living with or who have been affected by cancer (e.g., family, friends and/or caregivers). The six-week program offers workshops to help cancer survivors to better manage their health and daily lives. Participants will learn about: techniques to deal with issues such as frustration, fatigue, pain, poor sleep and living with uncertainty; setting priorities; relationships; nutrition; communicating effectively with family, friends and health professionals; making decisions about treatment and complementary therapies; and appropriate exercises for regaining and maintaining flexibility and endurance. The leaders are volunteers, many of whom are cancer survivors.

The National Cancer Institute and American Cancer Society "Springboard Beyond Cancer" online program provides "Action Decks" with information and audio recordings on cancer-related topics and advice on actions to take. The Post-Treatment deck aims to help survivors self-manage their health, deal with challenges and prevent new ones, and includes information sets on mindfulness and relaxation, fear of recurrence, distress, fatigue, brain fog and memory problems, sexual health, hot flashes, healthy eating, physical activity, and getting support in the workplace and from the health care providers.

A Cochrane review of home-based survivorship programs that had at least two of the following – educational, physical and psychological – interventions, found moderate quality evidence showing short-term improvements in quality of life, but lower quality evidence indicating reduced fatigue, insomnia and anxiety (Cheng, 2017).

Potentially of relevance to cancer survivors, Guided Self-Determination (GSD), a person-centred reflection and problem-solving method, has been offered to youth and young adults managing Type 1 diabetes to help improve their motivation for daily care and develop their skills to address difficulties in self-management. Group-based and individual GSD sessions have been offered. Various studies at six- and 12-month follow-up have shown improvements in reduced diabetes related distress; results have been mixed in terms of improved glycaemic control (Haas, 2017) (Mohn, 2017) (Zoffmann, 2015).

## Types of Peer Support

The types of peer support models offered to cancer survivors range from informal support and in-person and online support groups to matched support from a formally trained peer. In Figure 6, the Mental Health Commission of Canada outlines the spectrum of approaches to peer support (Sunderland, 2013).



**Figure 6. Spectrum of mental health peer support**

### INFORMAL PEER SUPPORT

Naturally occurring, voluntary, reciprocal relationship(s) with peers one-to-one or possibly in a community

### CLUBHOUSE/WALK IN CENTRE

Mainly psychosocial and social recreational focus with peer support naturally occurring among participants

### SELF-HELP, MUTUAL PEER SUPPORT

Consumer operated/run organizations/activities/programs, voluntary, naturally occurring, reciprocal relationships with peers in community settings e.g., housing, social/recreational, arts/culture, traditional/spiritual healing, recovery education/work, anti-discrimination education/work, human rights/disability rights education work

### FORMALIZED/INTENTIONAL PEER SUPPORT

Consumer run peer support services within community settings (either group or one-to-one) focusing on issues such as education, employment, MH systems navigation, systemic/individual advocacy, housing, food security, internet, transportation, recovery education, anti-discrimination work, etc.

### WORKPLACE PEER SUPPORT

Workplace-based programs where employees with lived experience are selected and prepared to provide peer support to other employees within their workplace

### COMMUNITY CLINICAL SETTING PEER SUPPORT

Peer support workers are selected to provide support to patients/clients that utilize clinical services, e.g., Outpatient, A.C.T teams, Case Management, Counselling

### CLINICAL/CONVENTIONAL MH SYSTEM-BASED PEER SUPPORT

Clinical setting, inpatient/outpatient, institutional peer support, multidisciplinary groups, recovery centres, or Rehabilitation Centres Crisis response, Crisis Management, Emergency Rooms, Acute Wards

## Individual Peer Support

Peer support is an important component of the emotional support services provided by several survivorship programs, whether centre-based, community-based or online. These programs are often integrated into treatment and survivorship programs and yield high levels of satisfaction for both parties. For example, at Princess Margaret, formally trained Healing Beyond the Body (HBB) volunteers provide: 1) emotional support by listening to patients, answering questions, offering encouragement, reflecting back their strengths and resources, and helping them feel understood and supported; 2) information about treatment and its side effects, clinic procedures and the cancer care system; 3) coping and stress-management strategies; 4) help seeking and gaining the skills find the information they need and accessing hospital- and community-based services; and 5) help preparing for appointments and questions they want to ask providers. The Patient and Caregiver Support Program at Memorial Sloan Kettering Cancer Centre in New York connects survivors with trained volunteers who have been through cancer treatment. These conversations can take place in person, over the phone, or via email.

At Wellspring, each new client meets with a peer support person upon entry to the program. Peers assess client needs, suggest relevant and appropriate programs, and help them navigate the programs and services through the various stages of cancer and survivorship. Wellspring, in collaboration with the Odette Cancer Centre, is launching a peer-led program to help survivors identify their needs and concerns and transition from treatment to survivorship and community services. Peer training is based on the coaching model. The Cancer Hope Network in New Jersey matches patients with trained peer volunteers who had similar experiences. Free one-on-one confidential support is offered along the continuum from diagnosis through survivorship. In Australia, Cancer Connect Peer

Support provides one-on-one telephone support from a trained volunteer who has had a similar experience. They provide both practical information and emotional support, listening with understanding and sharing their experiences and ways of coping. The Macmillan Living with Cancer and Beyond program in the U.K. offers a range of peer support – from hospital-based support, Expert Patient Programs and befriending, linking patients with those with similar experiences. Some peer programs are supported by clinical nurse experts, but most are supported through charities and volunteer communities.

### *Peer Support Groups*

Most survivorship programs at cancer centres, and several community and web-based services, offer support groups. These groups can be effective in creating peer networks, offering relational and informative support, and helping participants feel understood and reassured (Cipolletta, 2019). However, some studies and experts suggest relatively few cancer survivors take advantage of support groups, and those who do are predominantly of a higher socioeconomic status, female and younger compared to nonparticipants, and are potentially individuals whose mental health needs are already met (Graham, 2016).

Formal group support sessions are increasingly being offered online. For example, the Cancer Council in Australia's Online Community offers online discussion forums, support groups and blogs to connect and support survivors in sharing their experiences. Other organizations provide an online platform to facilitate social networking. Wellspring offers a different workshop each month. These include music, journaling, expressive therapy, meditation and mindfulness, self-compassion and art therapy. Be Well Talks are an hour and a half presentations by experts and professionals on pertinent topics. These have been in person, but are being moved to a webinar format.

Social networking is also a common method of peer support. The American Cancer Society's Cancer Survivors Network (CSN) is a free, social networking site available internationally to cancer survivors and caregivers where they can share their stories, experiences and practical information after treatment for cancer. CSN has over 3.6 million users annually from over 200 countries. The most commonly-used site features are discussion boards (81%), the search function (64%) and the member resource library (50%). There is ongoing evaluation of the site to inform improvements to usability, reach, recruitment, retention and potential health impacts (Fallon, 2018). Of note, social networking has not always been found to add benefit and should be designed and implemented in a way that mitigates potential negative consequences for some users (Corbett, 2018).

Online interaction with peers, including social networking, is also well-received by adolescent and young adult survivors. The evidence shows significant improvement in their psychologic wellbeing, knowledge, confidence, coping, self-efficacy and interpersonal skills through such interactions (Zebrack, 2012). The ReCaPTure LiFe (Resilience and Coping skills for young People To Live well Following cancer) – led by CanTeen in Australia – is an online support group for young cancer survivors led by a counsellor. Participants connect with other young cancer survivors to share stories and coping strategies in two separate six-week, 90 minute sessions.

While many support groups are structured and part of survivorship programs, some, like the Cancer Treat Club, are less formal community-led initiatives. Supported by Weston Park Cancer Charity and Macmillan in the U.K., the Cancer Treat Club is open to adults aged 40 to 60 with cancer. They meet once a month to participate in activities such as theatre, cinema, lunches, dinners, dancing, spa visits, yoga, shopping, etc. Some youth and young adults report that they are not interested in attending conventional cancer "support groups," but prefer age-relevant opportunities to meet and interact with peers. Examples of such groups include the I'm Too Young for This Annual OMGStupid Cancer Summit, paintball tournaments, happy hours and golf tournaments, Young Adults triathlons, and First Descents outdoor adventures (kayaking, rock climbing, surfing).



## Group Educational Sessions

Many group sessions for cancer survivors include educational workshops and information sharing. While they differ in focus, content and duration, several educational interventions for survivors have been found to improve pain, physical functioning, depressive symptoms, stress and quality of life when compared to usual care (Stanton, 2006) (Luckett, 2011).

Group educational sessions are offered by many organizations in conjunction with other survivorship programs. For example the Hope & Cope program at the Jewish General Hospital in Montreal offers the Focus on the Future six-week workshop. Sessions cover: 1) rights returning to work, disclosure, etc.; 2) diet and nutrition; 3) medical management and side effects; 4) fatigue, brain fog and adapting to the workplace, including work-life balance; 5) recommended exercise and how to integrate it into everyday life; and 6) emotions, stress, distress, self-care and how to move forward. In addition to the professional presenter, a volunteer attends each session and leads the discussion among survivors, including discussions on goal setting and how to apply the learnings. There is also a post-treatment support group that runs once a month. Wellspring offers an eight-week Children's and Parent's Program led by a nurse and social worker that includes communication and therapeutic play activities for children aged 5 to 12 whose parents have cancer. Parents meet separately at the same time. Family counselling is available by referral and there is an online educational guide for parents.

The BC Cancer Agency works in partnership with regional health authorities and its mandate covers the full spectrum of cancer care from prevention, screening, diagnosis, treatment, follow-up and palliative care to research and education. It promotes numerous support groups and education sessions at the six cancer centres across the province. For example, Victoria has a Cancer Transitions two-day workshop for those who have completed treatment. The modules include exercise, nutrition, lingering treatment side effects, fear of recurrence and moving forward. There is a mix of group discussion, exercise and presentations, with time for questions. The After Active Treatment program in Vancouver is a four-part series, offered twice a year, that provides information and resources to survivors. Themes include living with uncertainty, relationships and body image. The What Now? program in Surrey is a monthly drop-in session for survivors and their families focused on education, information and discussions on the transition from treatment to healing and recovery. As well, BC Cancer's psychosocial oncology program offers an eight-week memory and attention training program provided by clinical counsellors and social workers, and an eight-week mindfulness program.

The Penny Brohn U.K. charity evaluated its living with and beyond cancer services, including Living Well courses and follow-up support, in North England, South Coast, Midlands, London and South East and South West. In most regions, six weeks after the classes, clients reported statistically significant changes in their lifestyle, ability to self-manage, main cancer-related concern, wellbeing and patient activation (Seers, 2018). Improvements to spiritual, emotional and functional wellbeing were found at 12 months in Bristol (Polley, 2016). Table 4 provides some additional examples of trade-marked group programs.

**Table 2. Examples of trade-marked group survivorship educational programs**

Group program	Description
Southlake Regional Health Centre, Stronach Regional Cancer Centre, Breast Cancer Survivorship, <i>Cancer Transitions: Moving Beyond Treatment™</i>	An evidence-based survivorship program developed by the Cancer Support Community and LIVESTRONG to support and empower breast cancer survivors as they transition from active to post treatment. Sessions include the following topics: Get Back to Wellness: Take Control of Your Survivorship; Emotional Health and Well-Being: From Patient to Survivor; Nutrition Beyond Cancer; Exercise for Wellness: Customized Exercise; Medical Management Beyond Cancer; and Life Beyond Cancer. Participants meet for 2.5 hours a week for six weeks. Group support, discussion and exercise are incorporated into each session. An interactive approach facilitates group support and discussion, as well as practical tools and information to encourage short and long-term goal setting for physical and emotional wellbeing. The full course is offered 3 to 4 times per year. The Cancer Transitions website is also a resource for those who cannot attend the onsite course.

Group program	Description
Cedars Sinai, Wellness, Resilience and Survivorship Programs, Mental Health <i>Emerging from the Haze™</i>	A six-week psycho-educational program that helps patients cope with the effects of "chemo brain," and addresses issues like finding or remembering words, concentration, multitasking and memory. Clients are breast cancer survivors who have completed chemotherapy and/or radiation therapy within the past two to 24 months. The program is also part of a study and participants are surveyed at various times about their level of cognition, symptoms and quality of life. There is also a follow-up session one year after completion of the program.
Cedars Sinai, Wellness, Resilience and Survivorship Programs, Mental Health, <i>GRACE (Growing Resiliency and Courage)™</i>	A small group six-week program for cancer survivors that focuses on cultivating resiliency, managing perspective, coping with fear and discovering meaning and purpose after a cancer diagnosis.
UNC Lineberger Comprehensive Cancer Center <i>Cancer Transitions: Moving Forward After Treatment™</i>	A free four- to six-week group program to help cancer survivors and their caregivers make the transition from active to post-treatment. Topics include: physical activity; nutrition and healthy eating; Get Back to Wellness; medical care; coping with stress; and emotional health. Each weekly session lasts for 2- 2.5 hours.

### Online Information and Educational Support

Information delivery and communication via the internet and social media have been found to encourage cancer patients to actively participate in their health-related decisions and improve their self-confidence and communication skills (Zebrack, 2012). There are several examples of web-based support for cancer survivors. Most organizations mainly use the internet to provide information tailored to survivors' needs. Some organizations provide comprehensive online tools like My Journey Kit and the Cancer Survival Toolbox.

The Breast Cancer Network Australia's My Journey Kit is an online tool which provides evidence-based information and insight from others diagnosed with breast cancer. Its information is tailored to all stages of breast cancer, including survivorship. Available via computer, tablet and smartphone, it has multimedia content including videos, webcasts and podcasts, as well as updates on research and clinical trials. The Cancer Survival Toolbox was developed in the U.S. by the National Coalition for Cancer Survivorship in collaboration with the Oncology Nursing Society, Association of Oncology Social Workers, and the National Association of Social Workers. The Toolbox is a series of audio informational talks to help people develop the skills to better understand and meet the challenges associated with their cancer. The online audio sessions cover basic skills and special topics, including Living Beyond Cancer, which addresses: the physical effects of cancer and its treatment; medical records needed to maintain a personal health history; sexuality and fertility; family relationships; the emotional aspects of cancer, including anxiety, depression, grief and distress; health directives, wills and trusts, power of attorney and financial planning; and how to live with uncertainty.

The following are additional examples of online educational and interactive services. The Australian Cancer Council offers webinars on survivorship and work and cancer that include presentations on various topics, with the opportunity to interact via a chat box with the presenters and participants. The webinars are recorded enabling people to view them at their convenience. The Massachusetts Cancer Prevention and Control Network Survivorship Workgroup and Digital Pitch offer a multimedia Wellness Guide for adult cancer survivors. The guide provides survivors with information to help them improve their quality of life physically, socially, intellectually, spiritually, emotionally and occupationally. Life Beyond Lymphoma is an online interactive post-treatment service with tailored information on lymphoma survivorship based on a series of questions. It provides information about follow-up care, disease concerns, late effects of treatment, health lifestyles, understanding emotions, getting emotional support, changing in relationships, work and school life and financial issues. In addition to the online Q&A and information, it provides guidebooks, tip sheets, videos and social media platforms.

## Higher Risk

Importantly, some cancer survivors with a higher acuity needs require more intensive professionally-led psychosocial interventions. According to one expert who provides one-on-one psychosocial counselling, common concerns of survivors' in their adaptation to survivorship relate to meaning making and resilience within the "new normal," as well as feelings of isolation and distress, relationships and attachment, employment and economic issues, and ongoing cancer symptoms. A common trigger for emotional distress can relate to reminders that the experience of cancer may not be over or that it may come back, including ongoing late effects, new symptoms and anniversaries. These can result in sadness, frustration or anger about not being able to put the experience behind them. Many in distress have a past history of trauma which presents itself or worsens post treatment. Ideally, interventions for these individuals emphasize "post-traumatic growth."

Experts suggest that one-on-one treatment for the mental health concerns of cancer survivors, such as depression and anxiety, should follow the existing evidence-based pathways (i.e., screening, treatment planning, referral, intervention, relapse prevention, and follow-up) (Saracino, 2019) (Gudenkauf, 2018). Post-traumatic stress disorder (PTSD) induced by life-threatening medical events has been associated with adverse physical and mental health outcomes, and studies suggest that early intervention in cancer and heart patients, emphasizing cognitive behavioural therapy or meaning-making, can reduce its symptoms (Birk, 2019). While services, such as cognitive behavioural therapy, can be integrated with a survivorship program, such services can also be successfully provided in the community. Whereas, a higher severity of psychological symptoms and cancer-specific conditions – such as fear of recurrence and existential distress (questioning of central life goals, identity and philosophy of life) – are potentially more adequately addressed within the cancer care system and survivorship programs. Moreover, survivors with physical health problems could benefit from psychosocial care that is integrated with their rehabilitation (Recklitis, 2017) (Vehling, 2018).

A number of evidence-based interventions exist for cancer-related distress as exemplified in Table 5. These interventions have been shown to improve quality of life, as well as contribute to reduced recurrence and improved survival rates. Best practices promote tailoring interventions to individual psychological needs, including stress management and coping, problem-solving, adherence to medical and supportive care recommendations, health behaviour change, social support, sexual health and intimacy, emotional processing and expression, and assertive communication (Gudenkauf, 2018).

**Table 3. Evidence-based interventions for cancer-related distress**

<b>Intervention type</b>	<b>Clinical focus</b>	<b>Key psychosocial outcomes</b>
<b>Cognitive and Behavioural Cancer Stress Management (CBCSM)</b>	Structured approach, providing psychoeducation Approach-oriented coping and problem-solving strategies (e.g., cognitive reframing, health behaviour change, interpersonal skills), enhancing self-efficacy Relaxation skills training	Improvements in depressive symptoms, anxiety, self-efficacy, fatigue, social functioning, perceived social support and benefit finding
<b>Supportive-Expressive Therapy (SET)</b>	Promotes peer social support and expression of emotions and existential concerns Focuses on facing and grieving losses	Improvements in depressive symptoms, hopelessness and helplessness, trauma symptoms and social functioning
<b>Meaning-Centered Psychotherapy (MCP)</b>	Targets psychological, existential and spiritual distress in advanced survivors	Improvements in quality of life, depressive symptoms, and hopelessness
<b>Mindfulness-based interventions</b>	Based in contemplative spiritual traditions Promotes non-judgmental awareness of the present	Improvements in anxiety, depressive symptoms, fear of recurrence, fatigue and physical function

<b>Intervention type</b>	<b>Clinical focus</b>	<b>Key psychosocial outcomes</b>
<b>Acceptance and Commitment Therapy (ACT)</b>	Uses acceptance and mindfulness strategies Promotes commitment to behaviour change, increasing psychological flexibility and adaptability	Some evidence for reduced anxiety and depressive symptoms
<b>Behavioural lifestyle interventions</b>	Focused on increasing healthy behaviours, primarily physical activity	Improvements in fatigue, depressive symptoms, body image and health-related quality of life
<b>Yoga</b>	Mind-body intervention involving meditation, breathing and body postures	Improvements in fatigue, sleep, health-related quality of life, anxiety and depressive symptoms
<b>Couples-focused interventions</b>	Psychological interventions for cancer survivors and their partners	May impact quality of life, distress, relationship functioning and physical symptoms

(Gudenkauf, 2018)

Many cancer centres and some community-based organizations offer psychosocial services by referral within their programs, but they are not always integrated with the cancer care system. “Many cancer centres lack a system of psychosocial care that is integrated with the cancer care of the patient” (Fann, 2012). Other clinic-based survivorship programs and agencies refer to community-based mental health services. The inclusion criteria and extent of the intervention can differ greatly among programs. Providers are generally social workers, psychologists, psychiatrists and occupational therapists.

As an example of a cancer centre-based mental health service, the Psychosocial Oncology division at Princess Margaret provides care for patients and their families with moderate to severe psychosocial needs related to distress and other psychosocial issues. It also supports oncology teams in their management of mild psychosocial distress at the point of care. The Distress Assessment and Response Tool (DART) self-assessment is used to measure patient distress, anxiety, depression and social difficulty. Results go to the patient and the EMR for access by the oncology team, and are used by a multidisciplinary team to develop a triaged response plan. Those found to be in low distress are referred to a DART volunteer who is trained to provide basic information and peer support and to link patients to self-directed resources, such as the Canadian Cancer Society and Wellspring. Moderate to high distress is flagged for the nurse or oncologist, who conducts a further assessment and creates a personalized care plan, which can include a range of interventions from acknowledgement and normalization of concerns to referral for services such as home care, medication or spiritual care. In cases where patients are experiencing high levels of distress, the health care team considers referral to specialty services in psychosocial oncology, such as social work, psychiatry and palliative care. A pilot study of the DART program found 88% of patients felt the program improved their ability to communicate their symptoms and concerns to the health care team and about half said participating in the program had a positive effect on them (Li, 2016).

The BC Cancer Agency’s provincial psychosocial oncology program provides services for patients up to 18 months post treatment. It provides six-sessions of individual counselling for patients and families either in-person or by phone related to coping with emotions, challenges in relationships and dealing with the practical and financial concerns. Wellspring, a community-based organization, provides three, one-on-one counselling sessions to high-need clients. Support includes addressing distress, anxiety and depression, adapting to survivorship, meaning making, addressing past trauma, relationships and attachment, and return to work.

As an example from the cardiac care system, as part of the Cardiac Rehabilitation Program at the Ottawa Heart Institute, patients have access to social workers to assist them in obtaining medications, applying for financial assistance, ensuring appropriate discharge and return to the community, providing emotional support and counselling to alleviate depression, anxiety and adjustment to their

health condition, communicating with family, accessing resources, and providing advocacy and liaison services with other health care professionals and community resources.

The NHS Improving Access to Psychological Therapies (IAPT) program in the U.K. is an example of a more comprehensive universal program. Since 2018, all local health services are required to provide evidence-based treatment for anxiety and depression (according to NICE guidelines) that is integrated with care pathways for people with long-term physical health conditions and medically unexplained symptoms. The program includes routine outcome monitoring. A priority of the service is supporting people to find or stay in work. As part of the Macmillan supported Living with and Beyond Cancer Programme, participants are referred for this psychosocial support in their community based on their Holistic Needs Assessment and Recovery Package.

Importantly, psychosocial interventions may need to be tailored to meet the needs of certain population groups. For example, Indigenous cancer survivors could benefit from programs specifically tailored to their individual circumstances, including personalized spiritual care, involvement of family members and elders, and connection to other Indigenous cancer survivors (Cavanagh, 2016). Nueva Vida, a non-profit organization in the Washington DC area, provides free, comprehensive and culturally competent services to Latinas affected by cancer. The Mental Health Survivorship program includes bilingual and bicultural psychosocial interventions to support survivors and their caregivers through facilitated, targeted group, and individual therapy.

### **Targeted Psychosocial Programs**

There are a number of evidence-based, topic-specific programs that address specific symptoms of distress among cancer survivors.

#### ***Individual***

ConquerFear is a theory-based metacognition intervention that addresses the way in which individuals think about their thoughts related to fear and worry about cancer recurrence. ConquerFear entails one-on-one counselling for those with high levels of fear of recurrence at three to six months post treatment. Participants receive five 60- to 90-minute sessions with a clinical psychologist or psychiatrist, along with “homework” thereafter. In the first session, the Fear of Cancer Recurrence Inventory (FCRI) scale is used to assess the roots of their fear and its severity. The program aims to help people accept and distance themselves from fear and worry, postpone worry and focus their attention where they want it. The approach does not challenge patients’ beliefs about risks of recurrence, but aims to help clients live with uncertainty. The intervention is comprised of screening, values-based goal setting, attention training, detached mindfulness, challenging metacognitions, recognizing signs and symptoms of recurrence, and empowerment to seek information from health professionals. In the last session, survivors are taught strategies to avoid relapse.

Patients with a score above a clinical cut off that indicated a persistent anxiety that interfered with their ability to live life to the fullest were included in a randomized controlled trial of the program. High satisfaction and retention were found compared to clients receiving five sessions of attention control, using relaxation therapy. Participants had greater reductions in fear of recurrence after therapy and at three and six months. Those with greater symptoms at baseline benefited the most from ConquerFear. While relaxation therapy helped those with milder distress, it was insufficient for those with high levels of fear, as it did not target key cognitive processes (Butow, 2019) (Butow, 2017). The program is now offered throughout Australia. Internet and group versions and information sheets are being piloted.

Although it is not a survivorship program, Managing Cancer and Living Meaningfully (CALM) addresses tenets of distress that could be applied to survivors experiencing severe distress. CALM is a brief, semi-structured, evidence-based intervention designed to help people with metastatic cancer and their loved ones manage the practical and profound problems associated with advanced disease.

Reduction of psychological distress and prevention of future distress are the primary goals of this therapy. CALM focuses on four areas: 1) symptom management and communication with health care providers; 2) changes in self and close relationships; 3) spirituality, sense of meaning and purpose; and 4) sustaining hope and facing mortality. The therapy consists of three to six individual sessions delivered over three to six months by a range of health care professionals. Research conducted over the past decade has shown that CALM is a feasible, acceptable and effective therapy in reducing and preventing distress and depressive symptoms in individuals with advanced or metastatic cancer (Rodin, 2018).

### *Group*

The Healing Journey Program was developed based on published research and the book by the same name by Alastair Cunningham. The program is offered at Princess Margaret and in the community by Wellspring and Hearth Place Cancer Support Centre and provides psychological and spiritual tools “to promote inner harmony, peace and healing.” The program has been found to reduce anxiety and depression, restore a sense of control, and relieve symptoms such as fatigue, nausea and pain.

The Healing Journey Program has six levels. Participants must start at Level 1 and proceed through the levels in order, the latter of which are particularly applicable to survivors. Levels 1 to 5 are each 10 weeks in length. Level 1 Coping with Cancer Stress, teaches participants the benefits of helping themselves through supportive care and provides an introduction to stress management techniques, such as deep relaxation, healthy thought management, visualization, expression of emotions and goal setting. Level 2 Skills for Healing builds on the skills and techniques learned in Level 1 through meditation, journaling, consulting an inner healer, letting go of resentments, spiritual aspects of healing, and supportive group discussion. Level 3 Steps Toward Spiritual Healing explores the impact of cancer on spiritual identity and wellness. It offers psycho-spiritual skills to help reduce frustration and resentments and encourage feelings of peace and equanimity. Level 4 Becoming Authentic synthesizes the strategies and topics covered in Levels 1 to 3, and further explores personal healing through authenticity, autonomy and acceptance. Level 5: A New Earth uses the concepts and models from the previous levels to review and discuss chapters in a book by Eckhart Tolle. Level 6 Healing by Expanding the Sense of Self is an advanced 10-month weekly course for those who want to explore the potential of their minds to assist in their physical, mental and spiritual healing in more depth. The course has a manual that describes the weekly topics and provides assignments for home study. The workbooks and audio files are available online and follow the same content as the “live” program.

The Stress Management and Resilience Training (SMART) Program is offered at the Mayo Clinic. The program consists of two 90-minute group training sessions, a brief individual session and three follow-up telephone calls. In a randomized controlled trial, participants experienced a significant improvement in resilience, perceived stress, anxiety and overall quality of life at 12 weeks compared with baseline, while none were found in the control group, suggesting that brief, group-based stress management interventions may be effective (Loprinzi, 2011). In an evaluation of the Macmillan Cancer Support anxiety course, the majority of participants reported improvements in their symptoms and physical and emotional wellbeing, as well as a reduction in anxiety. Participants felt better equipped with tools to manage their anxiety. They also reported that they felt happier, more empowered and less alone.

There are examples of programs and approaches for adolescents and young adults related to other chronic conditions that could be of relevance. Project ACCEPT (Adolescents Coping, Connecting, Empowering, and Protecting Together) is a group intervention offered to adolescents and young adults newly diagnosed with HIV in the U.S. and Africa. It was developed based on the Disability-Stress-Coping model and incorporates skills-building activities guided by Social Cognitive Theory. The 8- to 12-session program – some individual and the remainder facilitated group sessions – aims to address personalized stigma, disclosure concerns and self-image, develop coping skills, and provide social support among peers. Participants reported feeling less socially isolated as a result of connecting with

peers (Zebrack, 2012), and reduced personalized stigma, disclosure concerns and negative self-image (Harper, 2014).

### *Online Mental Health Interventions*

#### *Design and Content*

Many people living with and beyond cancer may face barriers – such as time, distance and resource constraints – accessing needed services. Web-based interventions and apps have the potential to address some of survivors' unmet needs in an accessible, cost-effective and convenient manner. There is increasing evidence that some survivors prefer web-based supports and applications to help them address their mental health and quality of life concerns because of the convenience and reduced burden and disruption to their lives. Reviews, including randomized controlled trials, have found online mental health interventions – including cognitive behavioural therapy, lifestyle interventions and symptom management – to be feasible and acceptable to cancer survivors (Post, 2016) (Forbes, 2019).

Telehealth – videoconferencing or Skype-based interventions – is increasingly being offered to survivors who do not live near to program sites or who are unable to travel to them. For many, personalized care from a distance and the reassurance from access to a health care professional are important (Cox, 2017). Cancer survivorship programs are increasingly offering mental health counselling services and group programs via videoconference. BC Cancer and Wellspring offer one-on-one counselling online and Wellspring offers some of its educational programs exclusively via videoconference.

In addition to ensuring the content of technological interventions is evidence-based, research findings emphasize the importance of designing them to match survivors' unique needs and capabilities, and having professional and end-user input into design to maximize their benefit (Corbett, 2018) (Borosund, 2018) (Cox, 2017). Cancer survivors – as well as health care providers and ehealth experts – want web-based applications and apps to have ease of access, availability at the user's selected time, user friendliness, understandable language, several brief sections rather than longer ones, and applicability (including content specific to their changing needs and stepped-care based on the stage of the survivorship trajectory). Privacy and confidentiality are also of importance (Corbett, 2018) (Borosund, 2018) (Cox, 2017) (Willems, 2017).

Most adolescent and young adult survivors are active users of digital technology and comfortable using various applications. Key concerns for this group include social isolation and health-related anxiety (Lathren, 2018). In one study, half of younger survivors kept in contact with others they met during treatment and 12% were in contact with those they had not met in person. Related to their online preferences, two-thirds of adolescent and young adult survivors wanted to access to online clinical information, over half wanted to access online chat rooms and support groups, and 44% wanted online counselling or psychological support (Abrol, 2017). Other studies also show the desire of younger survivors to have online access to clinical information in order to increase their knowledge and self-efficacy, including age appropriate information and interactive options via websites and games (Zebrack, 2012). Additionally, the use of text messages as reminders to schedule and attend follow-up screening and other appointments, as well as tailored suggestions for community resources, is also feasible and acceptable among adolescent and young adult survivors (Casillas, 2017).

#### *Outcomes*

While there is increasing evidence to support the efficacy, accessibility and acceptability of online evidence-based mental health interventions for the general and specific patient populations, there are fewer studies focusing on best practices and outcomes associated with interventions uniquely for cancer survivors (Leykin, 2012). While such studies are underway (e.g., an Acceptance and Commitment Therapy based cognitive behavioural intervention for mild to moderate anxiety and depression) (Mendes-Santos, 2019), further work is needed to identify appropriate online strategies for

addressing mental health issues and promoting behaviour change, as well as the optimal stage in cancer survivorship to offer such interventions (Corbett, 2018).

Nevertheless, some studies suggest that online supportive interventions are associated with reduced cancer-related distress, depression and fatigue, and improved coping, social functioning and health-related quality of life in cancer survivors (Forbes, 2019) (Willems, 2017), as well as increased knowledge, self-efficacy, self-management and adherence among young survivors (Zebrack, 2012). Some types of online interventions have been found to be as effective as face-to-face interventions (although outcomes can vary by age), and the level of adherence to the intervention is strongly associated with outcomes (Kim, 2016) (Borosund, 2018) (Huber, 2018).

Cancer Chat is an online group therapy delivered by psychologists, social workers and Masters' level nurses trained in interactive online therapy. Sessions are usually topic-specific, including managing insomnia-CBT, body image, sexual functioning, advanced cancer, fear of recurrence, caregiver support and return to work. Group therapy sessions run for 8 to 10 weeks and are open to participants from across Canada. There is psychosocial screening for the intake of participants to ensure appropriate matching and to screen for high levels of distress. Referrals are provided if depression or other types of distress are detected. Sessions have one or two facilitators and tend to have 8 to 10 participants. Once initiated, the groups are closed to new members and can be tailored to meet participants' needs. As part of therapy sessions, Cancer Chat uses guided imagery, art work, relaxation exercises, self-management tools, thought journals and homework segments. Satisfaction is generally high in post session evaluations. Depending on the program, improvements have been found in coping, body image, sexual functioning, sleep disturbance, quality of life and other cancer-related symptoms, such as distress. Based on evaluation results, some groups are being refined and tested in funded trials. One project is working on an AI design to develop an "online co-facilitator."

The Kanker Nazorg Wijzer (Cancer Aftercare Guide) is a web-based support tool implemented at 21 Dutch hospitals for cancer survivors with psychosocial issues. A randomized controlled trial found increased emotional and social functioning and reduced depression and fatigue at six months compared to a waitlist control, but not at 12 months, suggesting the intervention can expedite psychological recovery for survivors post treatment (Willems, 2017).

Insight is a computerized cognitive rehabilitation program for cancer survivors with persistent cognitive symptoms offered at the Sydney Survivorship Centre and trialled at 18 sites across Australia. Participants receive a 30-minute telephone consultation outlining strategies to address general cognition, memory, concentration and multitasking. Participants then participate in a 15-week home-based neurocognitive learning program. Based on the neuroplasticity model, it targets cognitive processing systems to improve the speed and accuracy of information processing. It focuses on visual precision, divided attention, working memory, field of view and visual processing speed. A randomized controlled trial found better cognitive outcomes in the intervention group, as well as significantly lower levels of anxiety, depression and fatigue (Bray, 2017).

### *Mindfulness and Spiritually*

Mindfulness training can assist people in coping with emotional, physical, psychological and existential challenges. In systematic reviews and meta-analyses, mindfulness-based stress reduction has been shown to produce a moderate to large positive effect on the mental health of people living with and beyond cancer, including reduced anxiety, depression, fear of recurrence, fatigue and physical function (Zhang, 2016) (Hulett, 2016) (Zainal, 2013). Psychoneuroimmunology (PNI) is a relatively new field of study that looks at the interactions between the central nervous system and immune system. A review of studies measuring PNI outcomes associated with mindfulness-based stress reduction, found intervention groups had better mental health outcomes and improved or stable neuroendocrine-immune profiles compared to control groups. The author suggests future research



should focus on the minimum dose and duration needed to improve or stabilize neuroendocrine-immune function, as well as effective settings for the intervention (Hulett, 2016).

Mindfulness tools can be used in other psychosocial approaches. Acceptance and Commitment Therapy (ACT) uses mindfulness strategies and a focus on behaviour change to improve psychological adaptability. ACT is potentially a tool for working toward acceptance of relapse and other fears related to cancer. Small studies have shown ACT to be effective in reducing anxiety and depressive symptoms, though not through a comparison with cognitive behavioural therapy. Expressive Writing, where survivors write about their emotional experiences and benefits derived from the cancer experience, has been shown to reduce physical symptoms and cancer-related medical visits. But, effectiveness depends on the writing topic and level of cancer-related avoidance (Gudenkauf, 2018).

Mindfulness and similar programs are offered to cancer patients and survivors by several cancer centres and community organizations. Some organizations have standalone mindfulness programs; others embed mindfulness sessions within an overall survivorship wellbeing program or combine it with yoga in relaxation programs. Examples of cancer centres that include mindfulness approaches in the survivorship programs include: centres affiliated with the BC Cancer Agency, Cancer Care Manitoba and Princess Margaret Cancer Centre in Canada; Roswell Park Comprehensive Cancer Centre Survivorship Clinic; Simms/Mann UCLA Center for Integrative Oncology and UNC Comprehensive Cancer Center in the U.S.; Cancer Council ENRICHing Survivorship Program and Sydney Survivorship Centre at Concord Hospital in Australia, and Centre for Cancer Rehabilitation in Stockholm, Sweden.

Participants in Mindfulness-Based Interventions at Princess Margaret reported that they felt better able to address many of their concerns associated with going through the cancer journey, including depression, anxiety, body image distress, pain, and living with uncertainty and fear of recurrence. The BC Cancer Agency found that their mindfulness program resulted in significant benefit for patients in decreased stress, anxiety and pain.

An example of a community-based program that integrates mindfulness is the Relaxation and Visualization program at Wellspring. It is a weekly drop-in program that includes 15 minutes of relaxation exercise, 45 minutes talking about coping with cancer and its aftermath, and 30 minutes of visualization exercises. Survivors tend to use the program to address lasting side effects, fear of recurrence and depression. Wellspring also offers energy programs, including therapeutic touch and reiki and “Chilife,” a combination of qigong and tai chi adapted for cancer patients which includes 10 minutes of meditation, a qigong sequence and then tai chi movements.

A few survivorship programs include spiritual support as one of the objectives of their offerings; some of these programs (e.g., Penny Brohn, the Healing Journey) explicitly provide integrative physical, emotional, psychological and spiritual support. Studies assessing the association between spirituality and religion (e.g., beliefs, experiences, coping) and mental health (e.g., depression, anxiety, wellbeing) in cancer patients have used heterogeneous measures and produced inconsistent results. Few spiritually-based interventions have measured religious or spiritual constructs. One meta-analysis found a modest correlation between the two that depends on how spirituality/religion and mental health were assessed (Salsman, 2015). Another review found few associations between religion/spirituality and psychological wellbeing in cancer survivors, and concluded that psychological wellbeing may depend to some extent on belief systems. However, attempting turning to religion without a significant prior relationship with it or minimal spiritual behaviours may result in diminished wellbeing, and, while struggling with or questioning one’s belief system may be associated with lower levels of wellbeing in early survivorship, this generally improves over time (Schreiber, 2012).

## Physical Activity

### Exercise

Supervised, community-based exercise programs have been found to be effective and safe for cancer survivors of various ages and diagnoses. Interventions can include strength training, resistance training, walking, cycling, dance, yoga, qigong and tai chi. Numerous studies involving randomized controlled trials across the world have found improvements in strength, endurance, speed, flexibility and blood pressure, as well as health-related quality of life, self-esteem, body image, pain, fatigue, insomnia, cognitive functioning, emotional wellbeing, depression, anxiety, sexuality, and social support and functioning. Physical activity can also reduce morbidity and mortality, as well as excess weight, a risk factor for recurrence. Studies have also found participants are more likely to meet the recommended exercise guidelines and maintain adherence (Irwin, 2017) (Levin, 2015) (Livingston, 2015) (Rajotte, 2012) (Turner, 2018) (Grimmett, 2019) (Levin, 2015) (Mishra, 2012) (Demark-Wahnefried, 2018). Experts suggest that further evidence is required on how to sustain positive effects over time and key program attributes (e.g., mode, intensity, frequency, duration, timing) by cancer type and treatment.

Yoga has been shown in several studies to improve the health-related quality of life of cancer survivors and reduce fatigue and sleep disturbance compared with no therapy, and to reduce depression, anxiety and fatigue in the short term compared to psychosocial/educational interventions (Cramer, 2017). Additionally, meta-analyses have found lower quality evidence suggesting yoga might be as effective as other exercise interventions in improving quality of life, depression and anxiety and potentially be used as an alternative to other exercise programs (Cramer, 2017) (El-Hashimi, 2019).

Dance and music programs may also improve psychological and physical outcomes in people living with and beyond cancer. Randomized controlled trials have found that participation in dance programs improved self-reported quality of life (Bradt, 2015) (Sandel, 2005) and music therapy reduced anxiety, depression, pain and fatigue, and may have a small effect on heart rate, respiratory rate and blood pressure (Bradt, 2016).

Physical activity participation and adherence among cancer survivors tends to be low, and those who do tend to be of higher socio-economic status and in urban areas (Demark-Wahnefried, 2018). Many who do participate in exercise programs report that a clinician's referral influenced their decision to participate (Livingston, 2015). Two systematic reviews found behaviour change techniques that included goal setting, graduated tasks, individualized coaching, social support and instruction on how to change behaviour were most often related to participants meeting exercise recommendations and targets and continuing adherence (Turner, 2018) (Grimmett, 2019). Another systematic review suggests that cancer survivors want to participate in physical activity programs, but there is wide variation in exercise preferences. The review found that walking, morning programs, programs that could be adapted to home-based activities, and physical activity counselling provided by a fitness expert at a cancer centre were most preferred, suggesting programs tailored to survivors preferences, as well as ready information about programs, may optimize recruitment and adherence (Wong, 2018). Generally, stronger outcomes have been associated with clinic-based programs, but greater reach and reduced participant burden are associated with home-based interventions (Demark-Wahnefried, 2018). A study of the community-based TrueNTH Lifestyle Management program for prostate cancer survivors in Calgary found the following factors promoted access and participation: perceived benefits of participating (physical, psychological and social); facilitators of involvement (program design, initial free access, tailored to specific prostate cancer needs, psychosocial environment); and opportunities for improvement and sustainability (exercise as a part of standard care, cost, home-based options) (Culos-Reed, 2019).

There are numerous physical activity programs provided by cancer centres and community organizations that include exercise, dance, yoga, tai chi, etc. Several cancer centres have dedicated exercise facilities and offer regular weekly classes. Often physical activities and exercise are integrated into educational and group survivorship programs. Large cancer centres may have several exercise specialists on staff, including exercise physiologists, kinesiologists, occupational therapists, physiotherapists and other fitness experts. As well, many cancer centres have linkages and partnerships with exercise programs in the community, to which they refer people after completion of cancer treatment.

LIVESTRONG is a popular community-based survivors' group exercise program in partnership with the YWCA. This 12-week program meets twice a week for 90 minutes, using traditional exercise methods to ease participants back into fitness and help them maintain a healthy weight. Topics include: building muscle mass and strength, increasing flexibility and endurance, and improving confidence and self-esteem. Participants also learn about wellness, stress reduction and how to maintain healthy habits after the program ends. The LIVESTRONG at the YMCA program provides an individualized approach to recovery and tailors physical activities to match participants' comfort and ability. It also encourages them to interact with each other and share experiences. Trials have found improvements among program participants in the amount of exercise per week, the six-minute walk test and measures of quality of life (Irwin, 2017).

The Healthy Living after Cancer (HLaC) is a program offered by four Australian Cancer Councils. It is a free, evidence-based, six-month telephone-delivered post-treatment lifestyle coaching program. It provides behavioural theory based support related to physical activity, healthy eating and healthy weight. An evaluation of the program found a 57% retention rate and, among those who completed the program, improvements in weight, physical activity, and dietary intake/behaviour, quality of life, cancer-related side effects and fear of recurrence (Demark-Wahnefried, 2018).

## Rehabilitation

Some patients require more intensive physical rehabilitation post treatment. At Princess Margaret, all patients who complete their cancer treatment are referred to the Cancer Rehabilitation and Survivorship (CRS) program to undergo an assessment and develop a rehabilitation plan. Some are referred to programs in the hospital or the community. Others are referred to Cancer Rehabilitation and Exercise (CaRE), an eight-week program offered in groups at the centre or individually online, entailing one hour of education and one hour of exercise. Fitbits are provided for the duration of the program to allow patients to monitor their activities, and a new app is being introduced to aid the kinesiologist in developing, monitoring and adjusting individual exercise plans. Individuals with more than one cancer-related impairment are referred to a specialized rehab program at the Toronto Rehabilitation Institute, which includes one-on-one visits with an occupational or physiotherapist, social worker consults, massage and one-on-one neuropsychology for brain fog if required. Upon completion, clients return for reassessment by the CRS program and obtain further support or are discharged to the community.

The PINC & STEEL Cancer Rehabilitation supports cancer rehabilitation in New Zealand and Australia, and is extending its programs to the U.K., South Africa, Canada, USA, Brazil and Dubai. It offers three main programs delivered by certified PINC & STEEL cancer rehabilitation physiotherapists. One of the programs, Next Steps is a 10-week group exercise program for men and women who have finished cancer treatment. The program combines pilates, yoga and cardiovascular exercises in a workout designed to help rebuild strength, flexibility and stamina. The PINC Cancer Rehabilitation Program for women aims to improve cardiovascular fitness, strength, stamina, endurance, flexibility, metabolism, muscle tone and body composition after treatment. The STEEL Cancer Rehabilitation Program for men aims to improve strength, quality of life and sense of wellbeing. It is designed to help men regain physical strength, stamina, cardiovascular fitness, flexibility, endurance, metabolism, muscle tone and body composition, and to incorporate exercise into

their lifestyle. Both PINC and STEEL exercise focus on improving physical functioning to support return to work and living a productive life. Education sessions focus on fatigue management, return to work, sport and leisure activities. Other services include physiotherapy, physical and functional assessments, individualized clinical pilates, fatigue management, resistance training and exercise prescription.

Another example of a home-based rehabilitation program is the Ottawa Heart Institute's Cardiac Rehabilitation Program, which offers a three-month case-managed Home Program, including a coronary risk factor assessment, tailored individual goals and a home exercise program. There are 15 30-minute appointments, three at Heart Institute and the remainder by phone. Additionally, the six-month, web-based Cardio-Fit program is a home-based tailored exercise and physical activity program. There are five online physical activity planning tutorials (10 to 15 minutes each) and an online physical activity log.

## Primary Care

### Follow-up Care in the Community

As discussed above, the potential residual effects of cancer and its treatment are many – long-term symptoms, depression, anxiety, fear of recurrence, brain fog, pain, fatigue, insomnia, weight gain, body changes, early menopause, sexual health and fertility, and employment issues – and can emerge immediately or sometime after treatment. Survivors and their caregivers also may feel loss and isolated when they are discharged from the cancer system. Experts suggest part of survivorship services entail “rebuilding the person” and much of that is “downloaded” to primary care. Additionally, whereas in the past patients may have remained in the cancer system for some time, they are now being discharged more frequently and earlier.

Primary care providers play an active role in the treatment and care of those living with cancer and beyond, and primary care is increasingly positioned within the cancer care continuum. Several randomized control trials and other studies have shown cancer patients can safely transition to primary care for follow-up care, this care has outcomes similar to tertiary health care (Zhao, 2018) (Miedema, 2018) and it can be cost-effective (Wollersheim, 2018). The evidence also shows that primary care plays an important role in the detection of cancer recurrence (Rasmussen, 2018) (de Boer, 2018).

A review of the literature found that both family physicians and patients support a greater role for primary care in follow-up cancer care. This includes an increased role in care coordination, symptom and pain relief, screening, diagnosis and management of physical and psychological effects of cancer and cancer treatment, as well as health promotion, ongoing comprehensive care and palliative care (Meiklejohn, 2016). At the May 2019 meeting of the Cancer and Primary Care Research International Network, most participants agreed with the notion “that from the perspective of family physicians/general practitioners, management of patients during cancer treatment and survivorship is just as important as management of patients with high prevalence conditions, such as mental health issues and heart disease” (Cancer and Primary Care Research International Network Conference (CaPRI), 2019).

Nonetheless, there are patient, provider and health system barriers to effectively transition survivors to primary care (Miedema, 2018). Guidelines, approaches and practices for transitioning patients back to their primary care providers and follow-up cancer care vary significant nationally and internationally and by cancer centre. In some instances, there are formal guidelines and protocols; in others the process is more ad hoc (Meiklejohn, 2016). One literature review found limited evidence on best practices for implementing and evaluating transition models and a lack of guidelines that position transition models as usual care (Miedema, 2018). For primary care providers, many in the community feel ill-equipped or too busy to address the concerns of cancer survivors sufficiently. A Canadian study

found that primary care providers were only willing to assume exclusive responsibility for routine follow-up cancer care at an average of 2.5 to 3.2 years post treatment, depending on the type of cancer. Those already providing this type of care were willing to do so sooner (Del Giudice, 2009). According to most experts, access to team-based care within primary care is critical to providing comprehensive post-treatment care. Related to their needs and experiences, survivors have reported unmet needs (e.g., psychosocial support and information on possible long-term effects), insufficient involvement of family physicians in their care, concern about physician expertise in cancer management, concern that physicians are too busy, and a lack of continuity and consistency of care, making it difficult to address long-term issues. They also place a high priority on the role of follow-up visits in detecting recurrence and the role of primary care in providing reassurance and overseeing surveillance (Richards, 2011) (Khan, 2011) (Bock, 2018). Additionally, survivor characteristics and the type and severity of cancer can influence patients' preferred caregiver (Wieldraaijer, 2018).

Mental health issues, including depression and anxiety, are frequently dealt with at the primary care level post cancer treatment. Primary care providers play a central role in managing depression and concurrent physical comorbidities. There are numerous resources to inform this type of care, including a recent BMJ, "state of the art" review series on evidence-based guidelines and recommendations for screening, diagnosing and treating depression. The series covers various approaches, including guided self-help, psychological counselling, computerized cognitive behavioural therapy, cognitive behavioural therapy, problem-solving therapy, interpersonal psychotherapy, behavioural activation, and short term psychodynamic psychotherapy (Ferenchick, 2019) (Ramanuj, 2019). Moreover, some suggest that use of the Canadian Problem Checklist has been well integrated into the system.

### Survivorship Care Plans (SCPs)

Survivorship care plans (SCPs), which outline the survivor's health care history and status and recommendations for ongoing care, could play an important role in facilitating transitions from active treatment to primary care. Many Canadian and U.S. organizations recommend or require their use in this regard. However, the current evidence base is mixed in terms of the effectiveness of post-treatment SCPs. A study of the Ottawa Wellness Beyond Cancer program found most primary care providers reported that SCPs were useful in providing follow-up care recommendations (Rushton, 2015). Other studies support this finding and the importance of SCPs in the conveying information about cancer treatments, side effects and survivorship follow-up guidelines. They also facilitate improved communication and coordination of care with cancer specialists (Chaput, 2018). However, some studies have shown resource constraints and cost-effectiveness concerns have limited their uptake, and other studies have found no impact on patient or clinical outcomes, including Canadian randomized controlled trials that found no significant differences in terms of cancer-specific distress, health-related quality of life, patient satisfaction, continuity and coordination of care, and health service outcomes such as adherence to guidelines (Boekhout, 2015) (Grunfeld, 2011). Differences found in outcomes related to the use of SCPs have been attributed to varying content, format, timing and mode of delivery (Chaput, 2018). Additionally, while randomized controlled trials have not shown their effectiveness, qualitative and observational studies have found that survivors and primary care providers report they benefit from SCPs. A recent review of these trials, along with Canadian and American stakeholders' priorities, determined that the outcomes measured in the trials may not align with those of importance to patients and primary and tertiary providers. For example, primary care providers want SCPs to improve follow-up care role clarity, communication with cancer specialists, access to information (e.g., related to surveillance guidelines); and their understanding of and confidence in ongoing responsibilities (Urquhart, 2018). The Canadian study found, that to assume exclusive responsibility for follow-up cancer care, primary care providers require: 1) printed guidelines; 2) patient-specific information from the specialist; 3) expedited routes of re-referral; and 4) expedited access to investigations for suspected recurrence (Del Giudice, 2009).

Many cancer centres with survivorship programs develop survivorship care plans that are shared with primary care providers. As an example of a regional approach, the Living With and Beyond Cancer

Programme supported by Macmillan Cancer Support in the U.K. offers needs assessment and personalized care plan to those with a cancer diagnosis. These – as well as the treatment summary/discharge letter – are available electronically to all primary care providers. Additionally, it is a national policy that family physicians are required to undertake the cancer care review within three months of diagnosis, with a 95% adherence rate. The Macmillan program is also working to support primary care in improving patient information flow and their conversations with those living with cancer and beyond to support improved quality of survivorship care at the community level.

### **Integrated Frameworks and Models for Continued Cancer Care in Primary Care**

Several of the integrated care models and frameworks developed for primary care – the chronic care model, rehabilitation model, patient’s medical home, self-management model and collaborative care model – could serve as guidance for improved follow-up and psychosocial care for those living with and beyond cancer. Several – including the Improving Mood-Promoting Access to Collaborative Treatment (IMPACT), Primary Care Behavioural Health Model, and the Primary Care-Mental Health Integration initiative – have shown applicability and efficacy as integrated survivorship psychosocial care models (Strong, 2008) (Fann, 2009) (Fann, 2012) (Recklitis, 2017) (Robinson P J, 2016). In these models, behavioural/mental health professionals work collaboratively with primary care to provide assessments, consultations and brief mental health interventions, as well as referrals to mental health specialty care when needed. As part of the implementation of these models, several tools and strategies have been developed, including job descriptions, evidence-based interventions, clinical pathways, assessment measures, quality indicators, and scheduling and follow-up procedures (Recklitis, 2017). The Improving Access to Psychological Therapies (IAPT) programme in the U.K. also serves as an integrated care pathway model for people with long-term physical health conditions and medically unexplained symptoms.

The College of Family Physicians of Canada recently released an updated model for the Patient’s Medical Home in family practice which could also service a framework for better integrated cancer care. The model includes a focus on the broader patient’s medical neighbourhood, connected care and the importance of linkages and information sharing with hospitals, specialists, mental health and addictions, social and community supports, and others (College of Family Physicians of Canada, 2019). The Patient’s Medical Home model is also an important consideration because survivors are also at risk for additional long-term chronic conditions and added symptom burden, as well as health conditions associated with ageing, multi-morbidities that require ongoing treatment and management, as well as continued patient self-management (Cavers, 2018).

Collaboration between primary care and cancer specialists is also important for adult survivors of childhood cancer. There are guidelines for primary care providers, such as those published by the Children’s Oncology Group, that outline the clinical issues that may affect this group, including depression, stress and self-esteem, along with the potential impact on parental health. However, the evidence indicates that improved communication with and resources for primary care are required in this regard (Jain, 2019).

Experts also suggest that family physicians need to be better versed in the physical and mental health challenges faced by survivors, especially given the nature of the patient-provider relationship in primary care and that these issues are likely to emerge in primary care. There are models for improving this capacity in primary care. For example, Cancer Care Ontario’s (CCO) Primary and Community Care Program aims to ensure patients are supported by their primary care provider throughout their cancer experience and that they receive appropriate support and surveillance upon completion of active treatment. CCO’s Provincial Primary Care and Cancer Network Cancer Care Ontario includes a provincial lead, 21 regional primary care leads and 10 regional Indigenous leads who are responsible for engaging primary care with the cancer system. The Primary Care Cancer Survivorship Program of Western Massachusetts aims to provide primary care services and coordinate services, while people living with cancer and beyond are receiving care from the

oncologist. They also work closely with the oncology team in transitioning patient from active treatment to follow-up primary care. The Australian Cancer Survivorship Centre at the Peter MacCallum Cancer Centre works with providers in the community to build cancer survivorship capacity and supports a placement program in the cancer centre for family physicians and other primary care providers to be mentored and develop shared-care skills.

Additionally, some experts suggest that improving integrative care among primary care, specialists and cancer centres could take place within a quality improvement/management framework, potentially including health promotion, prevention and surveillance, management of the physical and psychosocial effects of cancer, management of multi-morbidities, patient experience, communication and care coordination, and clinical outcome measurement (Barbui, 2014) (Nekhlyudov, 2018).

## Return to Work

### Return to Work Needs

Employment is a significant concern for many people of working age living with and beyond cancer and they may experience different work-related challenges at various stages in their journey during and post treatment. Diagnosis entails disclosure to employers and the need for their flexibility during treatment and rehabilitation. Post-treatment, they may struggle in determining the right time to return to work, whether they can resume their previous role, and the appropriate scope, pace of work and level of productivity. Importantly, return to work issues can continue long into survivorship and workers' needs can change over time. While initial barriers tend to relate more to cancer and treatment-related issues, they become increasingly psychosocial and workplace related. One study of return to work found improved work functioning and decreased fatigue, cognitive and depressive symptoms in the first 12 months, which remained stable to 18 months, and social support from their supervisor was also associated with survivors' work functioning (Dorland, 2018). In a study of breast cancer survivors, a sizeable number of survivors reported a change in employment status, such as job loss, five to ten years after returning to work (van Maarschalkerweerd, 2019).

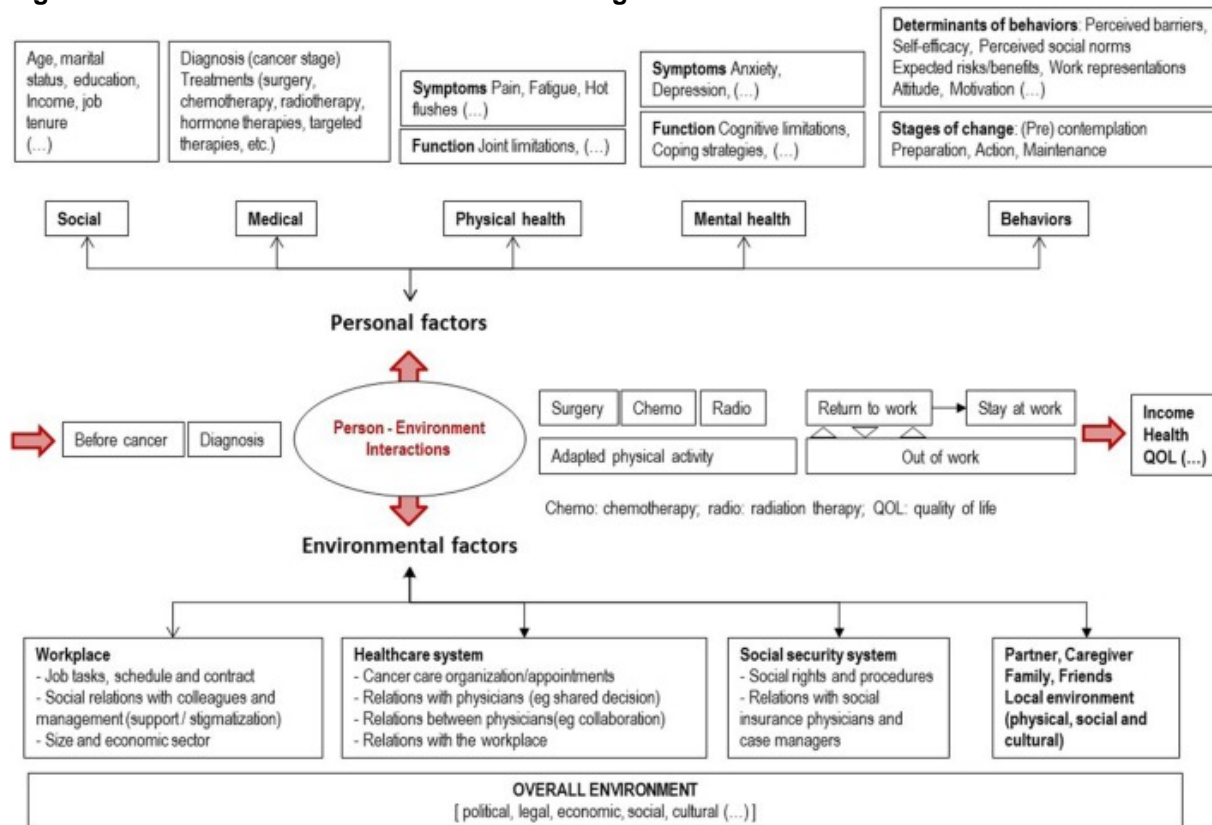
While cancer may change their perspectives about work and their career decisions, a systematic review concluded that employment was associated with enhanced overall quality of life for working age cancer survivors (Stone, 2017). In one study, survivors were likely to return to work earlier when they placed a higher value on the work, had a greater perceived work ability and job self-efficacy/confidence, as well as lower fatigue (Wolters, 2018).

As well, many face the additional pressure of financial stress due to reduced income as a result of their inability to work; some people do not have any benefits and those on long-term disability receive approximately two-thirds of their annual income. Moreover, diminished work capacity upon return to work can be accompanied by lessened income and financial hardship, and can result in increased distress, particularly among young adults (Stone, 2017).

Individual physical and psychosocial factors, the workplace social environment, workplace culture and demands, social support systems, and other supportive resources can all influence the ability of cancer survivors to return to work and their on-the-job performance (Sun, 2017) (Stergiou-Kita, 2014). Back in the workplace, survivors may experience physical limitations (such as fatigue and reduced strength) and cognitive challenges (such as brain fog). Psychosocial issues like fear of recurrence, depression, anxiety, lack of self-confidence and existential challenges related to the meaning of the work they perform can all influence their ability to work (Duijts, 2018) (Bijker, 2018) (Duijts, 2014) (Stone, 2017). Stigma and workplace discrimination are also significant concerns for cancer survivors (Stergiou-Kita, 2016), especially when their rights and interpersonal relationships are affected. Additionally, having the appropriate workplace accommodations can enhance survivors' abilities to stay or return to work (Stergiou-Kita, 2016). Fassier proposes the conceptual framework in Figure 7 for

assessing the various individual and environmental determinants associated with returning to work after breast cancer (Fassier, 2018).

**Figure 7. Determinants associated with returning to work after breast cancer**



(Fassier, 2018)

## Return to Work Interventions

As discussed above, returning to work is an ongoing process that entails planning and decision making related to work readiness and symptom management. Regarding strategies and programs to facilitate return to work, many cancer survivors need integrated support – and in some instances dedicated case management – from health and vocational professionals as part of the recovery process. Many returning to work need information and support with their return to work options, communication skills, disclosure and speaking with their employer regarding any functional limitations, their rights and the law, financial management, and navigating and fulfilling the prerequisites for accessing available benefits and assistance. Support can also include completing a self or professional work readiness evaluation, assessing of how their symptoms could affect work performance, defining work expectations and goals, and determining the requisite accommodations. Such accommodations could include: 1) graduated return to work plans and flexible scheduling; 2) modification of work duties and performance expectations 3) retraining and/or workplace supports; and 4) modifications to the physical work environment and/or adaptive aids and technologies. Survivors may need support understanding their rights, getting information about accommodations to address their needs, and negotiating with employers in this regard (Stergiou-Kita, 2016) (Stergiou-Kita, 2014) (Wolvers, 2018).

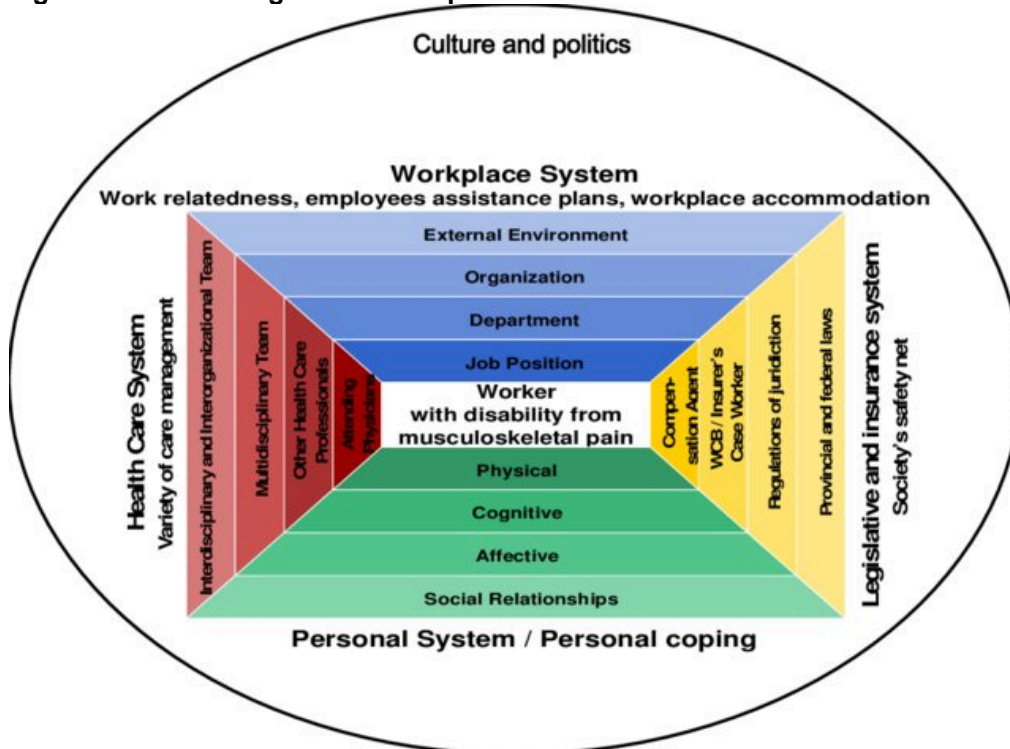
Evidence-based vocational rehabilitation, occupational counselling and return to work interventions post treatment have been shown to enhance physical (e.g., fatigue, strength and dexterity) and psychological (e.g., depression, anxiety and quality of life) readiness to return to work and workplace functioning (Hoving, 2009) (Dorland, 2018) (Hunter, 2017) (de Boer, 2015) (Leensen, 2017).



Interventions may need to be tailored to meet the needs of particular populations. For example, women report feeling more penalized and greater stigmatization in the workforce upon returning to work than men (Fassier, 2018), and people of low socioeconomic status are especially impacted by the financial effects related to the inability to work during cancer and its associated treatment costs. The Facilitator et Soutenir le retour au TRAvail apres un Cancer du Sein (FASTRACS) project in France aimed to reduce social disparities in employment after cancer through better understanding of barriers to return to work, intervention mapping and improved coordination among health services, workplace and insurance (Fassier, 2018).

Knauf presents an ecological, case management conceptual model for return to work related to occupational disability that could also apply to cancer (Figure 8) (Knauf, 2016).

**Figure 8. Case management conceptual model for return to work**



(Knauf, 2016)

### *Individual and Group Interventions*

Several cancer centres and community-based survivorship programs touch on return to work issues and provide education and advice as part of their offerings. Fewer provide dedicated one-on-one or group support in this regard. Examples of comprehensive return to work programs include BC Cancer’s Vocational Rehabilitation, Wellspring’s Returning to and Back at Work, Improving Access to Psychological Therapies (IAPT) in the U.K., and the Cancer Council’s Working Beyond Cancer and Redkite in Australia. Notably, the B.C. and Wellspring programs are run and administered by one person.

Insurance companies offer programs dedicated to returning to work, usually provided by third parties. Those on long-term disability are transitioned to a vocational rehabilitation specialist who assesses their readiness to return to work and may offer case management and rehabilitation services, if needed. Services can involve the development of a return to work plan, occupational therapy, work hardening programs, cognitive behavioural therapy or a progressive goal attainment program (PGAP).

Importantly, many people do not have disability insurance and there may be disagreement as to when the person is ready to return to work and at what capacity.

The BC Cancer Agency's Vocational Rehabilitation program provides one-on-one counselling (in-person or via videoconference) by a vocational rehabilitation counsellor and includes case management and referrals (e.g., to Work BC). Services include: aptitude, career exploration and return to work readiness assessments; vocational rehabilitation and career counselling; support with graduated return to work; return to school and retraining advice and support; priority setting; maintaining wellbeing and avoiding stress in the workplace; memory and attention adaptation training (MAAT); and understanding and accessing benefits and insurance. Tools offered include the "Cancer and Returning to Work" workbook which guides people in completing a return to work plan, job analysis worksheet and cognitive symptoms checklist at work. Group seminars are offered on topics such as managing returning to work, job searches, writing a resume and navigating insurance. The BC Cancer Agency's website has information on health insurance coverage, programs that help with medical costs, tips for writing a resume, and handouts, videos and other resources.

Wellspring provides back to work group workshops and information sessions for people in Toronto, Oakville, Brampton, London, Niagara, Calgary and Edmonton. "Returning to Work" is a six-week group educational and support program led by a specialized social worker and designed to support people in their return to work following an absence due to cancer. Topics include work readiness, employment accommodations, side-effects that impact job performance, goal setting, and preparation for the return. The program was previously delivered in-person and still is in Niagara and Calgary, but is now run via videoconference sessions elsewhere. It is accompanied by a workbook outlining session activities and homework. Wellspring provides two "Back at Work" online videoconference programs once a month. "Back at Work: Moving Beyond Cancer and Letting Go" addresses the isolation people feel when they are back at work and aims to help people identify how the cancer journey impacts their work life and provide strategies for moving beyond cancer. "Back at Work: Managing Stress at Work" addresses how stress can affect work performance and provides strategies for managing stress at work, including how to deal effectively with workplace demands and conflicts.

In the "Money Matters" program, a case manager meets one-on-one with cancer patients who are unable to work to assist them navigating income replacement programs, drug coverage and community resources. The program also supports clients with the post-treatment return to work process, including assessing readiness, navigating the often confusing disability system, managing paperwork, and dealing with insurance companies, employers and government programs related to long-term disability programs. They are also supported by a five-part video series on "Understanding Long-Term Disability Benefits." The case worker meets with the client as often as necessary. Some clients need one or a couple of sessions; others require ongoing case management. One-on-one sessions can be face-to-face, online (via Facetime or Skype) or by telephone. For those facing employer-related issues returning to work (e.g., related to accommodation or job security), an employment law clinic offers one-hour of free advice. There is also a human resources career coach clinic for those without jobs where participants receive assistance creating a CV and searching for employment.

Return to work support is provided as part of the Improving Access to Psychological Therapies (IAPT) in the U.K., a national, integrative initiative focusing on providing treatment for anxiety and depression for all people with long-term physical health conditions. They offer free support if anxiety and depression are affecting work performance and for people planning to return to work. The program also helps people address disability discrimination and needed accommodations at work, as well as issues such as redundancy, unfair dismissal, holidays and grievances. The program also works with employers to help them understand how anxiety and depression can affect work, and provides them with advice and sources of additional information.

In Australia, the Cancer Council provides a national pro bono return to work program that connects people with a volunteer human resources advisor in the community. Advice is available by telephone or email, and interpreter services are available. For people experiencing issues in their current job, the HR advisors provide advice on: disclosure of a cancer diagnosis and confidentiality obligations; flexible working arrangements; leave and salary during sick leave; managing expectations of employers and colleagues; and discrimination. For people returning to work, the advisors provide advice on: strategies for looking for and returning to work, including disclosure obligations; explaining the gap in a CV due to treatment; preparing a CV; and interviewing techniques. They can also connect clients with a lawyer, financial planner, accountant or HR/recruitment professional. A “Cancer, Work and You” booklet is also available.

Redkite provides information and one-on-one and group support to 15-24 year olds living with and beyond cancer to help them get back to work, study or training. Services are provided in Sydney, Melbourne, Brisbane and Perth Australia. Mentor social workers provide support with keeping up with school, applying for further study and assessing goals for study or work. They help clients set short- and long-term goals and develop a study and career plan. They also connect clients with resources, such as Thinking Ahead, a comprehensive guide to school, study and work developed with young people. Redkite also provides grants to those up to age 24 to help them achieve their work or study goals. These grants are available for up to two years after treatment ends and can be used for tutoring or coaching; courses; classroom support; materials and equipment; pursuing an interest, such as music, art or dance; and developmental therapy that is not available through the health system.

The WSIB Ontario Work Reintegration process that supports workers with workplace related injuries or illnesses, including cancer, and their employers achieve return to work through a comprehensive case management approach provides an example of the key elements of return to work support. The process provides and facilitates: return to work readiness assessments (including the workers’ workplace duties and requirements and health status); clinical support and guidance; a return to work plan with work and recovery goals and activities; vocational rehabilitation and graduated “work harding” services; negotiating and implementing workplace accommodations with the employer; community-based mental health services; and job-search support and retraining when a return to the existing job or accommodated work is not possible. WSIB’s internal return to work program also includes support through their Healthy Workplace Centre, peer-to-peer support, a social worker case manager, telephone-based mental health counselling, and an employment and family support program (EFAP).

### *Primary Care*

Primary care providers report that a significant part of their role in cancer survivorship care relates to return to work. This role can include support with regular (re)assessments, paperwork for disability and insurance benefits, and interaction with employers related to their understanding of the patient’s health, recovery trajectory and requirements for accommodation. They emphasize the importance of this role for their young adult survivors. Primary care providers report that often their cancer survivor patients need more services and support in rehabilitation, occupational therapy and physical fitness training. A recent review of the literature found little evidence on the role of the family physician related to cancer and return to work guidance and support. The study found that many lacked sufficient knowledge about work-related issues and access to guidelines and strategies in this regard (de Boer, 2018).

### *Web-based Interventions*

There are several online supports related to cancer and return to work. In Canada, Cancer and Work is a website developed with contributions from interdisciplinary clinicians, legal experts, policymakers and academics. It provides detailed information and resources about returning to work for cancer

survivors, health care providers and employers. For survivors, the website provides the following types of information:

- *Returning to Work/Staying at Work*: understanding current abilities and challenges; communicating with the health care team; strategies to improve work abilities; identifying supports; developing a formal return to work plan; preparing for the first days, weeks and months back at work; monitoring progress; and managing workplace expectations
- *Cancer's Impact on Work & Strategies*: physical symptoms; fatigue; exercise tips; nutrition; sleep; pain; communication challenges; cognitive symptoms; stress, anxiety and depression
- *Return to Work Communication and Teamwork*: communicating with the health care team, employer and workplace upon diagnosis, while off work and when returning to work; disclosure; workplace return to work practices and policies; key questions to guide a return to work plan; how to negotiate work accommodations; back at work; staying connected with co-workers when off work; talking with colleagues when back at work; communicating with insurance providers; questions about disability insurance; and roles of professionals
- *Assessment of your Work Abilities*: assessment of physical abilities; energizers and drainers tool; fatigue tracking tool; assessing your cognitive abilities; psychological self-assessment tools; readiness to return to work; professional assessments; assessing job demands ; understanding job characteristics; job analysis worksheet; reviewing the job description for essential and non-essential tasks; estimating a typical workday with a task analysis worksheet; using information from the national occupation classification system; and creating a job assessment
- *Finances and Disability*: government and private programs, and short term and long term disability benefits
- *Workplace Accommodations*: job accommodations for cancer-specific issues and other disabilities; adaptive aids and technology; ergonomic and adaptive technology assessments; accommodation responsibilities
- *Workplace Wellbeing*: changing your job situation; changing unhelpful thoughts and feelings; using the "Changing unhelpful thoughts" worksheet; using the ABC model to manage anxiety; changing reactions to negative work stress; negotiating healthy boundaries; assertiveness; honest and balanced relationships; exercise tips to improve fitness and get ready for work
- *Changing Jobs and Looking for Work*; changing work priorities; job searches; informational interviewing; resume writing; job interviews; disclosure during a job interview; career exploration
- *Caregivers*: rights at work; financial support for time off; compassionate care benefit; fatigue management strategies; job accommodation options; changes in the caretaker role; strategies for being a caretaker of a cancer survivor
- *Law, Policy, and Practice Information*: human rights; legal questions and answers; legal resources; employment standards law; union help; workers' compensation; links to services and resources

Cancer + Careers is a New York-based non-profit organization. It provides workplace-related resources and programs for those diagnosed with cancer, cancer survivors and health care providers, including online, in-print and in-person expert advice, interactive tools and educational events that address the practical and legal challenges related to work and cancer. "Back to Work After Cancer" resources include learning about how: cancer affects work life and the job; to take advantage of legal protections; to re-enter and get back into a routine; to evaluate readiness; to develop a back to work plan; to gain confidence; and the insurance and the law. There is an online discussion platform on various topics with career coaches. Other resources include information on "Recasting Yourself after Cancer," "Addressing Comments at Work," "Setting Professional Boundaries," "Your Mindset" and "Relieving Stress." The website also provides resources for exploring job options, looking for work, a resume review service, interviewing methods and finding meaningful work. Cancer + Careers also hosts workshops, webinars and teleconferences, provides educational videos, and hosts an annual conference. The website also has a checklist, manual, legal information and guidance for health care providers, and provides professional in-service training courses.

The Work after Cancer website is funded by Cancer Australia and is a resource to support those working during and after cancer. It provides advice to people diagnosed with cancer, their loved ones, clinicians and employers about their options, rights and responsibilities. The site provides information on: the basics of work after cancer; strategies for work after cancer; finding a professional with expertise in return to work; self-support in return to work; legal rights and responsibilities; and financial assistance. The Cancer Council in Australia offers webinars on survivorship and work. They include presentations and an opportunity to share a common experiences in real-time and to interact via a chat box with the presenters and participants. Registrants are provided a link to the webinar recording, a copy of the power point and a list of resources for future reference.

Workplace Strategies for Mental Health, with funding from the Great-West Life Centre for Mental Health in the Workplace, supports the Working Through website for those experiencing mental health challenges, including those related to life threatening illnesses like cancer. The site provides online peer support, as well as videos, templates and questionnaires with various strategies to address workplace issues and the return to work process. Other resources are entitled: Supporting Employee Success; Being a Health Advocate, Plan for Resilience; Stress Strategies; and Requesting Accommodation.

### *Publications*

The “Handbook of Return to Work” – authored by Canadian and American experts – is a synthesis of clinical and occupational interventions to support people in returning to work and sustaining employment after an injury or serious illness, as well as approaches to improving various re-entry outcomes. Information is accessible and covers theory, research and interventions, with an emphasis on evidence-informed approaches to planning for, returning and staying at work. It covers motivation to return to work; economy of gains and losses; barriers to return to work; behavioural and cultural change; program evaluation in return to work; and working with stakeholders in return to work processes. Condition-specific chapters, including “improving work outcomes among cancer survivors,” outline best practices for returning and staying at work across medical and psychological diagnoses. The handbook is meant to be a resource for health, rehabilitation, clinical, counselling and industrial psychologists, rehabilitation specialists, occupational and physical therapists, family physicians, psychiatrists, physical medicine and rehabilitation, occupational medicine specialists, case and disability managers, and human resource professionals (Schultz, 2016).

The U.S. National Coalition for Cancer Survivorship publication, Working it Out, describes cancer patients’ legal rights related to employment. It provides suggestion on how to avoid cancer-related employment problems and describes steps to consider if people believe they have been discriminated against. Documents include: How Employment Discrimination Laws Protect Cancer Survivors; What Can I Do to Avoid Discrimination?; and What Can I Do to Enforce My Legal Rights? (Hoffman, 2012).

## Conclusion

Cancer survivors have a variety of physical, mental health and psychosocial needs, depending on the individual, cancer type, stage of diagnosis, treatment regimen and time since treatment ended, many of which are not met. While recommendations and guidelines for survivorship programs include individualized survivorship care plans and risk-stratified pathways of care, the nature of these care plans vary greatly across programs – and may not address psychosocial or financial/return to work needs – many survivors do not have access to such programs or receive a survivorship care plan post treatment. The Macmillan Living with and Beyond Cancer Programme is an example of a universal single point of contact, offering a Recovery Package that includes a Holistic Needs Assessment, care plan, referrals to various local health and social services, and facilitating communication among specialists, primary care and patients.

Multimodal, interprofessional and, in some instances, multi-agency approach to survivorship programs are recommended, and can include: 1) standalone, multimodal survivorship programs within cancer centres; 2) programs and services embedded within the cancer treatment system; and 3) community-based and regional programs. Survivors at all levels of risk can benefit from an à la carte selection of programs and services to meet their unique needs. Access to integrative programs has shown better client outcomes related to adherence to guidelines, recurrence, access to integrative services and wellbeing. However, the extent of access to these services varies greatly, especially for those not in close proximity to cancer centres and other integrative programs, and for those with fewer resources and lower socioeconomic status.

Survivorship programs at many cancer centres, and several community-based organizations, offer a wide range of services that address survivors' psychosocial wellbeing. Peer support, social networking, educational programs and interventions, and exercise, meditative and recreational programs can all enhance survivors' mental health and wellbeing. Cancer survivors with a higher acuity of mental health needs also require more intensive professionally-led psychosocial interventions. These services are available, depending on the program, by referral within the survivorship program, the cancer centre or hospital, or in the community. The inclusion criteria and extent of the intervention differs greatly among programs. For example, some programs apply formal screening for distress, others do not. Some programs offer time-limited counselling; others provide longer-term support, as required. The Improving Access to Psychological Therapies (IAPT) program in the U.K. is an example of a universal chronic care program, requiring all local health services to provide evidence-based treatment for anxiety and depression that is integrated with the care pathways of people with long-term physical health conditions.

As well there are a number of targeted, evidence-based in-person, telephone and online individual and group interventions have proven to be effective in addressing cancer-related psychosocial concerns. As well, online supports and applications – including cognitive behavioural therapy, lifestyle interventions and symptom management – have been found to be feasible and acceptable to cancer survivors, and to be associated with reduced distress and improved coping, self-efficacy and health-related quality of life. However, programs could benefit from more evidence on best practices and outcomes associated with interventions uniquely for cancer survivors.

Employment is also a significant concern for many people of working age living with and beyond cancer, and they may experience different work-related physical, cognitive and psychosocial challenges at various stages during and post treatment. Return to work support is important for working-age cancer survivors because it addresses the financial stress and lost income many experience, and because employment has been associated with enhanced overall quality of life in survivors. Several cancer centres and community-based survivorship programs touch on return to work issues and provide education and advice as part of their offerings. Fewer – such as BC Cancer Vocational Rehabilitation and Wellspring Cancer Support Foundation – provide dedicated one-on-one

or group support in this regard. Primary care also plays an important role in return to work, including support navigating the insurance system and interaction with employers, but greater knowledge and capacity are needed in this regard. The WSIB Ontario Work Reintegration process provides an example of the key elements of return to work support. As well, there are several online and written supports for return to work, including Cancer and Work in Canada, Cancer + Careers in the U.S. and Work after Cancer in Australia. The “Handbook of Return to Work” – authored by Canadian and American experts – is a synthesis of clinical and occupational interventions to support people in returning to work and sustaining employment after an injury or serious illness.

Many cancer centres and survivorship programs use the term “discharged to the community.” Discharge may be accompanied with a follow-up plan, referrals to community-based services and coordination with primary care. But, often this is not the case. Primary care plays an important role in the cancer care continuum, including the psychosocial and return to work needs of survivors. However, there are several patient, provider and health system barriers to effectively transition survivors to primary care, including the flow of information, continuity of care, the readiness and capacity of primary care, and inconsistent access to team-based care within primary care. Further initiatives to address these barriers are required, including consideration of existing integration models (which include psychosocial components) that could serve as guiding frameworks for improved coordination, continuity and quality of care. Examples include the Chronic Care Model, Patient’s Medical Home, Primary Care Behavioural Health Model, Primary Care-Mental Health Integration initiative, and Improving Access to Psychological Therapies (IAPT) program.

Employment is a significant concern for many people of working age living with and beyond cancer, and they may experience different work-related challenges at various stages during and post treatment. Return to work support is important because it addresses the financial stress and lost income many experience, and because employment has been associated with enhanced overall quality of life in survivors. Several cancer centres and community-based survivorship programs touch on return to work issues and provide education and advice as part of their offerings. But fewer provide dedicated one-on-one or group support in this regard

There are many examples of integrative, multimodal cancer survivorship programs in Canada and internationally. The programs vary in their design, structure and program offerings, including the extent of their psychosocial and return to work services. Survivors who access these programs can benefit greatly; however, many do not have access to or benefit fully from the offerings. More systematic, universal approaches may result in more survivors getting the supports they need, and the psychosocial, mental health-related and return to work programs described in this environmental scan may inform the augmentation of existing programs, along with input from survivors, clinicians and the evidence.

## Appendix A - Key Informants

Name	Position, Organization
<b>Alexandria Woodside</b>	Program Coordinator Living Beyond Cancer, Cancer Survivorship Program Memorial Sloan Kettering Cancer Centre, New York, New York
<b>Barry Bultz</b>	Director, Dept. of Psychosocial and Rehabilitation Oncology, Tom Baker Cancer Centre, Professor and Head, Division of Psychosocial Oncology, Daniel Family Leadership Chair in Psychosocial Oncology, Cumming School of Medicine, University of Calgary
<b>Claudia Campos/ Laura Logie</b>	Chief Programs Officer and Mental Health Director/ Director of Research Nueva Vida, Washington DC
<b>Georgina Wiley</b>	Treatment and Recovery Advisor MacMillan Cancer Support, U.K.
<b>Helana Kelly/ Michael Jefford</b>	Manager/Director Consultant Medical Oncologist, Director of the Australian Cancer Survivorship Centre. Professorial Fellow at the University of Melbourne Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre
<b>Hinda Goodman</b>	Oncology Program Coordinator Hope & Cope, Jewish General Hospital, Montreal
<b>Ilene Schiller</b>	Manager Financial & Workplace Programs, Wellspring, Toronto
<b>Jeff Sisler</b>	Executive Director of Professional Development and Practice Support, College of Family Physicians of Canada Family physician at the Family Medical Centre, Winnipeg Professor, Department of Family Medicine, University of Manitoba Vice-Dean of the Office of Continuing Competency and Assessment in the Rady Faculty of Health Sciences
<b>Judi Perry Brinkert</b>	Chief Mission Officer Wellspring, Toronto
<b>Kate Glaser</b>	Assistant Professor of Oncology Department of Cancer Prevention & Control Roswell Park Comprehensive Cancer Center Survivorship Clinic Buffalo, New York
<b>Lauren Knelson</b>	Project manager Adult Survivorship Program Dana-Farber Cancer Institute, Harvard Medical School Boston, Massachusetts
<b>Lisa Del Giudice</b>	Assistant Professor, Department Family & Community Medicine, University of Toronto Family physician at Sunnybrook Health Sciences Centre Regional Primary Care Cancer Lead – Toronto Central LHIN
<b>Lucy Holland</b>	Senior Research Fellow Queensland University of Technology Children’s Health Queensland Hospital and Health Services, Australia
<b>Mary Ann Baynton</b>	Program Director Working through it, Workplace Strategies for Mental Health, Canada
<b>Mary Jane Esplen</b>	Professor and Vice- Chair, Department of Psychiatry, Faculty of Medicine, University of Toronto Executive Director, de Souza Institute, University Health Network



	Clinician and Affiliate Scientist, Princess Margaret Cancer
<b>Mary Vachon</b>	Professor, Departments of Psychiatry and Public Health Sciences, University of Toronto; Psychotherapist and Consultant in Private Practice Clinical Consultant, Wellspring, Toronto
<b>Maureen Parkinson</b>	Vocational Rehabilitation Counsellor BC Cancer Agency, Vancouver
<b>Melanie McDonald</b>	Professional Practice Leader Patient & Family Experience, Survivorship and Primary Care Late Effects, Assessment and Follow-Up (LEAF) Clinic, Psychosocial Oncology Program, BC Cancer Agency, Vancouver
<b>Michael Feuerstein</b>	Editor, Journal of Cancer Survivorship. Research and Practice Department of Medical & Clinical Psychology, Uniformed Services University of the Health Sciences Washington, DC
<b>Myann Marks</b>	Program Manager Cancer Rehabilitation and Survivorship Program, Department of Supportive Care, Princess Margaret Cancer Centre, Toronto
<b>Phyllis Butow</b>	Director of Centre for Medical Psychology and Evidence-based Decision Making, University of Sydney National Health and Medical Research Council Principle Research Fellow Australia
<b>Richard Metcalfe</b>	Program Director Macmillan Living with and Beyond Cancer Programme Macmillan Cancer Support/South Yorkshire, Bassetlaw and North Derbyshire Cancer Alliance, U.K
<b>Sandra Koppert/ Brandon Hey</b>	Director, Programs and Priorities / Research and Policy Analyst, Mental Health Advancement Mental Health Commission of Canada
<b>Todd Leader</b>	Vice President Support Programs Canadian Cancer Society, Nova Scotia Division
<b>Victoria Hewitson</b>	Manager, Lost Time Claims, Service Delivery WSIB, Ontario

## Appendix B - List of Case Studies

Lead organization	Program name	Country
BC Cancer Agency	Psychosocial Oncology Program	Canada
BC Cancer Agency	Late Effects, Assessment and Follow-Up (LEAF) Clinic	Canada
BC Cancer Agency	Vocational Rehabilitation	Canada
BC Cancer Agency	Life after Cancer	Canada
Cancer and Work	Web-based information	Canada
Cancer + Careers	Return to Work web-based information	USA
CanTeen Australia, Youth Cancer Services,	Life After Treatment	Australia
CanTeen Australia, Youth Cancer Services,	ReCaPTure LiFe	Australia
Dana-Farber Cancer Institute, Harvard Medical School	Adult Survivorship Program	USA
Dana-Farber Cancer Institute, Harvard Medical School	Young adult programs	USA
de Souza Institute, , University Health Network	Cancer Chat Canada	Canada
Jewish General Hospital, Hope & Cope Wellness Centre	Focus on the Future	Canada
Macmillan Cancer Support	Living With and Beyond Cancer Programme (LWABC)	UK
MacMillan Cancer Support	Anxiety course	UK
Memorial Sloan Kettering Cancer Centre	Adult Survivorship Program	USA
Memorial Sloan Kettering Cancer Centre	Adult Long-Term Follow-Up Program	USA
Memorial Sloan Kettering Cancer Centre	Living Beyond Cancer , Resources for Life After Cancer	USA
Nueva Vida	Mental Health Survivorship	USA
Peter MacCallum Cancer Centre	Australian Cancer Survivorship Centre	Australia
Princess Margaret Cancer Centre	Healing Beyond the Body (HBB) Volunteers	Canada
Princess Margaret Cancer Centre	ELLICSR Health, Wellness & Cancer Survivorship Centre	Canada
Princess Margaret Cancer Centre, Department of Supportive Care	Cancer Rehabilitation and Survivorship Program	Canada
Princess Margaret Cancer Centre, Department of Supportive Care	Psychosocial oncology	Canada
Princess Margaret Cancer Centre, Department of Supportive Care Global Institute of Psychosocial Palliative and End of Life Care	CALM Managing Cancer And Living Meaningfully (CALM)	Canada and International

Roswell Park's Comprehensive Center's Survivorship and Supportive Care Clinic	Survivorship and Support Care Center	USA
Roswell Park's Comprehensive Center's Survivorship and Supportive Care Clinic	Adolescent and Young Adult Survivorship Center	USA
Tom Baker Cancer Centre	Department of Psychosocial and Rehabilitation Oncology	Canada
Sydney Survivorship Centre, Concord General Hospital, University of Sydney	ConquerFear	Australia
Wellspring Cancer Support Foundation	Overall Program	Canada
Wellspring Cancer Support Foundation	Peer support	Canada
Wellspring Cancer Support Foundation	Short-term professional counselling	Canada
Wellspring Cancer Support Foundation	The Healing Journey	Canada
Wellspring Cancer Support Foundation	Cancer Exercise	Canada
Wellspring Cancer Support Foundation	Relaxation & Visualization, Energy Services, Chilife	Canada
Wellspring Cancer Support Foundation	Brain Fog (Maximum Capacity)	Canada
Wellspring Cancer Support Foundation	Nourish	Canada
Wellspring Cancer Support Foundation	Family services	Canada
Wellspring Cancer Support Foundation	Workshops and Be Well Talks	Canada
Wellspring Cancer Support Foundation	Money Matters	Canada
Wellspring Cancer Support Foundation	Returning to work	Canada
Wellspring Cancer Support Foundation	Back at work	Canada
Other chronic conditions		
Workplace Strategies for Mental Health	Working Through It	Canada
Stroke Association (UK)	Life After Stroke Services	UK
Stroke Association (UK)	My Stroke Guide Intervention	UK
Stroke Association (UK)	Volunteer Program	UK
Workplace Safety and Insurance Board (WSIB)	Return to Work	Canada
Canadian Mental Health Association	Bounce Back	Canada

## Appendix C - Inventory of Cancer Survivorship Programs List

Lead organization	Program Name	Country
Breast Cancer Network Australia	My Journey Kit	Australia
Cancer Council	ENRICHing Survivorship Program	Australia
Cancer Council	Living Well After Cancer program	Australia
Cancer Council	Healthy Living after Cancer (HLaC)	Australia
Cancer Council	Cancer Connect	Australia
Cancer Council	Online and telephone support	Australia
Cancer Council	Webinars	Australia
Cancer Council	Working beyond cancer, workplace advisory services	Australia
Cancer Council Victoria	Wellness and Life After Cancer Program	Australia
CanTeen Australia, Youth Cancer Services,	Life After Treatment	Australia
CanTeen Australia, Youth Cancer Services,	ReCaPTure LiFe	Australia
Concord Cancer Centre	Sydney Survivorship Centre	Australia
Flinders Centre fo Innovation in Cancer, Cancer Australia	Work After Cancer	Australia
National Centre for Cancer Survivorship	Post-Cancer Resources	Australia
Peter MacCallum Cancer Centre	Australian Cancer Survivorship Centre	Australia
Peter MacCallum Cancer Centre	Thinking Ahead	Australia
Redkite	Education and Career Support and Grants	Australia
Sydney Survivorship Centre, Concord Clinical School, U of Sydney and 18 Australian sites,	Cognitive rehabilitation program (Insight)	Australia
Sydney Survivorship Centre, Concord General Hospital	ConquerFear	Australia
Victoria State, Department of Health and Human Services	Victorian Cancer Survivorship Program	Australia
de Souza Institute	Cancer Chat Canada	Canada
BC Cancer Agency	Psychosocial Oncology Program	Canada
BC Cancer Agency	Late Effects, Assessment and Follow-Up (LEAF) Clinic	Canada
BC Cancer Agency	Vocational Rehabilitation	Canada
BC Cancer Agency	Life after Cancer	Canada
Breast Cancer Action Ottawa	More than just Fitness	Canada
Canadian Cancer Society	Wellness Plan	Canada
Canadian Cancer Society	Life after Cancer Treatment	Canada
Canadian Cancer Survivor Network	Canadian Cancer Survivor Network	Canada
Cancer and Work	Cancer and Work	Canada

Cancer Care Manitoba, Patient and Family Support Services	Psychosocial Oncology	Canada
Cancer Care Ontario	Cancer Care Ontario Survivorship Program	Canada
CancerConnection.ca	CancerConnection.ca	Canada
CAREpath Incorporated	Navigation System™	Canada
de Souza Institute, University Health Network	Cancer Chat Canada	Canada
Tom Baker Cancer Centre	Dept. of Psychosocial and Rehabilitation Oncology	Canada
Gilda's Club	Transitions: From Recovery to Wellness	Canada
Hearth Place	Bouncing Back	Canada
Hearth Place	Healing Journey	Canada
Jewish General Hospital's Segal Cancer Centre, Hope & Cope Wellness Centre	Focus on the Future	Canada
Lymphoma Canada	Life Beyond Lymphoma	Canada
McGill University Health Centre	MUHC's Cancer Survivorship Program	Canada
McGill University Health Centre	Psychosocial Oncology (PSO) program	Canada
McGill University Health Centre	Cedars CanSupport [CanSupport des Cedrès]	Canada
North York General	Colorectal Survivorship Program	Canada
Odette Cancer Centre, Sunnybrook	Patient and Family Support Program	Canada
Ottawa Hospital	Wellness Beyond Cancer Program	Canada
Ottawa Regional Cancer Foundation	Cancer Coaching	Canada
Self Management British Columbia	Cancer: Surviving and Thriving Self- Management Program	Canada
Southlake Regional Health Centre - Stronach Regional Cancer Centre	Breast Cancer Survivorship	Canada
Princess Margaret Cancer Centre, Department of Supportive Care, Global Institute of Psychosocial Palliative and End of Life Care	CALM Managing Cancer And Living Meaningfully (CALM)	Canada
Princess Margaret Cancer Centre	Cancer Rehab and Survivorship Program	Canada
Princess Margaret Cancer Centre	Psychosocial Oncology	Canada
Princess Margaret Cancer Centre	Healing Beyond the Body (HBB) Volunteers	Canada
Princess Margaret Cancer Centre	ELLICSR: Health, Wellness & Cancer Survivorship Centre	Canada
Wellspring Cancer Support Foundation	Back at Work	Canada
Wellspring Cancer Support Foundation	Brain Fog (Maximum Capacity)	Canada
Wellspring Cancer Support Foundation	Cancer Exercise	Canada
Wellspring Cancer Support Foundation	Family services	Canada
Wellspring Cancer Support Foundation	Money Matters	Canada
Wellspring Cancer Support Foundation	Nourish	Canada
Wellspring Cancer Support Foundation	Peer support	Canada

Wellspring Cancer Support Foundation	Relaxation & Visualization, Energy Services, Chi life	Canada
Wellspring Cancer Support Foundation	Returning to Work	Canada
Wellspring Cancer Support Foundation	Short term professional counselling	Canada
Wellspring Cancer Support Foundation	The Healing Journey	Canada
Wellspring Cancer Support Foundation	Workshops and Be Well Talks	Canada
Women's College Hospital	After Cancer Treatment Transition Clinic (ACTT)	Canada
We Gather the Power	Life Force Course and Physical Training	Denmark
European Cancer and Work Network (CANWON)	European Cancer and Work Network	Europe
La Ligue contre le cancer	La Ligue contre le cancer	France
University of Lyon	Faciliter et Soutenir le retour au TRAvail apres un Cancer du Sein (FASTRACS)	France
Livestrong	LIVESTRONG Survivorship Centers of Excellence Network	International
Ovarian Cancer Research Alliance	Survivors Teaching Students	International
WaronCancer	WarOnCancer	International
Department of General Psychology, University of Padua, Padua, Italy	Psychoeducational Support Groups	Italy
	<i>Kanker Nazorg Wijzer (Cancer Aftercare Guide)</i>	Netherlands
Pinc & Steel Cancer Rehabilitation Trust	PINC and STEEL	New Zealand
Centre for Cancer Rehabilitation	Cancer Rehabilitation	Sweden
Swiss Cancer League	Outpatient oncological rehabilitation	Switzerland
Breast Cancer Care (UK)	Moving Forward after breast cancer treatment	UK
Community-based charity	CLAN (Cancer Support for All)	UK
MacMillan Cancer Support	MacMillan Cancer Support	UK
MacMillan Cancer Support	Living With and Beyond Cancer Programme (LWABC)	UK
Penny Brohn UK	Living Well With Cancer	UK
WaveWalkers	WaveWalkers	UK
Weston Park Cancer Charity Macmillan	Cancer Treat Club	UK
Albert Einstein College of Medicine	Psychosocial & Integrative Oncology Program; Bronx Oncology Living Daily - BOLD Program	USA
American Cancer Society	Cancer Survivors Network online social networking community	USA
American Society of Clinical Oncology	cancer.net Return to Work	USA
American Society of Clinical Oncology	Guidelines	USA
Cancer + Careers	Return to Work web-based information	USA
Cancer Hope Network	Volunteer training and support	USA
Cancer Legal Resources Centre	National Telephone Assistance Line/ Educational	USA

	Outreach, RTW	
CDC	National Cancer Survivorship Resource Center	USA
Cedars Sinai	Wellness, Resilience and Survivorship Programs, Exercise and Healthy Lifestyles	USA
Cedars Sinai	Wellness, Resilience and Survivorship Programs, Mental Health	USA
City of Hope		USA
Survivor Journeys	Survivor Journeys	USA
Fred Hutchison Cancer Centre	Survivorship Clinic	USA
Froedtert Hospital and Medical College of Wisconsin Clinical Cancer Center	Healing With Ballet	USA
Journey Forward, collaboration of organizations with a common goal of improving survivorship care, including Anthem Inc., Cancer Support Community, Genentech, National Coalition for Cancer Survivorship, Oncology Nursing Society, and UCLA Cancer Survivorship Center.	Survivorship Plan	USA
Livestrong	At the YMCA	USA
Massachusetts Cancer Prevention and Control Network Survivorship Workgroup, Government of Massachusetts	Wellness Guide for Cancer Survivors	USA
Mayo Clinic	Cancer survivorship clinics Breast cancer survivors clinic Gynecologic cancer survivors clinic Lymphoma survivors clinic	USA
Mayo Clinic	Stress Management and Resilience Training (SMART) Program	USA
MD Anderson's Cancer Center	Life after Cancer for Survivors	USA
Memorial Sloan Kettering Cancer Centre	Adult Survivorship Program	USA
Memorial Sloan Kettering Cancer Centre	Adult Long-Term Follow-Up Program	USA
Memorial Sloan Kettering Cancer Centre	Living Beyond Cancer , Resources for Life After Cancer	USA
Moffitt Cancer Center	Cancer Survivorship Clinic	USA
Youth Survival Coalition	Living Your Best Life With Breast Cancer	USA
National Cancer Institute	Adolescents and Young Adults with Cancer	USA
National Cancer Institute and American Cancer Society	Springboard Beyond Cancer	USA
CancerCare	Post treatment survivorship	USA
National Coalition For Cancer Survivorship	Cancer Survival Toolbox®	USA
National Coalition For Cancer Survivorship	Employment rights	USA
Nueva Vida	Mental Health Survivorship	USA
Oncolife	Survivorship Care Plan	USA
Riverside Cancer Institute, Riverside Healthcare	Riverside Cancer Institute Survivorship Program	USA

Roswell Park Comprehensive Cancer Centre Survivorship Clinic	Survivorship & Supportive Care Center	USA
Roswell Park Comprehensive Cancer Centre Survivorship Clinic	Adolescent and Young Adult Survivorship Center	USA
Simms/Mann UCLA Center for Integrative Oncology	Survivorship Clinic, including young adult services	USA
Springfield Medical Associates	Primary Care Cancer Survivorship Program	USA
St. Jude's	After Completion of Therapy Clinic	USA
The National Comprehensive Cancer Network	Life after Cancer	USA
UCLA Jonsson Comprehensive Cancer Center	UCLA-LIVESTRONG VITA Program	USA
UNC Comprehensive Cancer Center	Comprehensive Cancer Support Program	USA
UNC Comprehensive Cancer Center	Cancer Transitions: Moving Forward After Treatment™	USA
UNC Comprehensive Cancer Center	Physical Activity	USA
Valley Children's Healthcare	Childhood Cancer Survivorship Program	USA
Wellness House for Living with Cancer	Unique Boutique	USA
Winship Cancer Institute, Emory	Wellness for Living	USA
Winship Cancer Institute, Emory	Young Adult Cancer Survivorship Program	USA
American Cancer Society	Cancer Survivors Network	USA
University of Alabama at Birmingham	Harvest for Health	USA



## Appendix D - Inventory of Other Chronic Disease Programs List

Lead organization	Program name	Country
Stroke Foundation	Enable Me	Australia
Stroke Foundation	StrokeConnect program	Australia
AIDS Committee of Toronto	Employment ACTion	Canada
Canadian Mental Health Association	Bounce Back	Canada
Canadian Mental Health Association	Mental Health Works	Canada
St. Michael's Hospital	My BeST: Trauma Survivors' Network	Canada
Workplace Safety and Insurance Board (WSIB)	Return to Work	Canada
Workplace Strategies for Mental Health supported by Mental Health Works, the Mood Disorders Association of Ontario, and the Great-West Life Centre for Mental Health in the Workplace	Working Through It	Canada
Educational and Counselling Psychology, and Special Education, UBC, and Department of Psychology, The University of Texas at Arlington	Handbook of Return to Work	Canada and USA
Stroke Alliance for Europe	Stroke Alliance for Europe (SAFE)	Europe
German Stroke Foundation	STROKE OWL	Germany
Several	Guided self-determination (GSD)	International
Hersenletsel.nl	Hersenletsel.nl	Netherlands
Stroke Foundation	Community Stroke Advisors	New Zealand
Stroke Foundation	Return to Work programme	New Zealand
National Health Services	Improving Access to Psychological Therapies (IAPT)	United Kingdom
Stroke Association	Life After Stroke Services	United Kingdom
Stroke Association	My Stroke Guide Intervention	United Kingdom
Stroke Association	Volunteer Program	United Kingdom
Individually-led	Stroke Stories	United Kingdom
Social Security Administration	Ticket to Work	USA
University of Chicago, Illinois	Project ACCEPT (Adolescents Coping, Connecting, Empowering, and Protecting Together)	USA
Peter Munk Cardiac Centre	Cardiovascular Prevention and Rehabilitation Program	Canada
University of Ottawa Heart Institute Programs	Cardiac rehabilitation program	Canada

## References

- Abrol E, Groszmann M, Pitman A, Hough R, Taylor RM, Aref-Adib G. Exploring the digital technology preferences of teenagers and young adults (TYA) with cancer and survivors: a cross-sectional service evaluation questionnaire. *Journal of Cancer Survivorship*. 2017;11(6):670-82. Available from: <https://doi.org/10.1007/s11764-017-0618-z>.
- Barbui T, Björkholm M, Gratwohl A. Cancer survivorship programs: time for concerted action. *Haematologica*. 2014;99(8):1273-6. Available from: <https://doi.org/10.3324/haematol.2014.104059>.
- Barnett M, McDonnell G, DeRosa A, Schuler T, Philip E, Peterson L, et al. Psychosocial outcomes and interventions among cancer survivors diagnosed during adolescence and young adulthood (AYA): a systematic review. *Journal of cancer survivorship : research and practice*. 2016;10(5):814-31. Available from: <https://doi.org/10.1007/s11764-016-0527-6>.
- Bijker R, Duijts SFA, Smith SN, de Wildt-Liesveld R, Anema JR, Regeer BJ. Functional Impairments and Work-Related Outcomes in Breast Cancer Survivors: A Systematic Review. *Journal of occupational rehabilitation*. 2018;28(3):429-51. Available from: <https://doi.org/10.1007/s10926-017-9736-8>.
- Birk JL, Sumner JA, Haerizadeh M, Heyman-Kantor R, Falzon L, Gonzalez C, et al. Early interventions to prevent posttraumatic stress disorder symptoms in survivors of life-threatening medical events: A systematic review. *Journal of anxiety disorders*. 2019;64:24-39. Available from: <https://doi.org/10.1016/j.janxdis.2019.03.003>.
- Bock GHd. Patients' expectations and preferences regarding cancer follow-up care. Cancer and Primary Care Research International Network Conference (Ca-PRI) 2018; April 18-20; Groningen, Netherlands 2018. Available from: <https://ca-pri.org>.
- Boekhout AH, Maunsell E, Pond GR, Julian JA, Coyle D, Levine MN, et al. A survivorship care plan for breast cancer survivors: extended results of a randomized clinical trial. *Journal of cancer survivorship : research and practice*. 2015;9(4):683-91. Available from: <https://doi.org/10.1007/s11764-015-0443-1>.
- Borosund E, Mirkovic J, Clark MM, Ehlers SL, Andrykowski MA, Bergland A, et al. A stress management app intervention for cancer survivors: Design, development, and usability testing. *JMIR formative research*. 2018;2(2):e19. Available from: <https://doi.org/10.2196/formative.9954>.
- Bradt J, Dileo C, Magill L, Teague A. Music interventions for improving psychological and physical outcomes in cancer patients. *The Cochrane database of systematic reviews*. 2016(8):Cd006911. Available from: <https://doi.org/10.1002/14651858.CD006911.pub3>.
- Bradt J, Shim M, Goodill SW. Dance/movement therapy for improving psychological and physical outcomes in cancer patients. *The Cochrane database of systematic reviews*. 2015;1:Cd007103. Available from: <https://doi.org/10.1002/14651858.CD007103.pub3>.
- Bray VJ, Dhillon HM, Bell ML, Kabourakis M, Fiero MH, Yip D, et al. Evaluation of a web-based cognitive rehabilitation program in cancer survivors reporting cognitive symptoms after chemotherapy. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2017;35(2):217-25. Available from: <https://doi.org/10.1200/jco.2016.67.8201>.
- Butow P, Williams D, Thewes B, Tesson S, Sharpe L, Smith AB, et al. A psychological intervention (ConquerFear) for treating fear of cancer recurrence: Views of study therapists regarding sustainability. *Psycho-oncology*. 2019;28(3):533-9. Available from: <https://doi.org/10.1002/pon.4971>.
- Butow PN, Turner J, Gilchrist J, Sharpe L, Smith AB, Fardell JE, et al. Randomized trial of ConquerFear: A novel, theoretically based psychosocial intervention for fear of cancer recurrence. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2017;35(36):4066-77. Available from: <https://doi.org/10.1200/jco.2017.73.1257>.
- Canadian Association of Nurses in Oncology Adult cancer survivorship: A self-learning resource for nurses. 2011. Available from: [https://www.cano-acio.ca/page/survivorship\\_module](https://www.cano-acio.ca/page/survivorship_module).
- Canadian Partnership Against Cancer. Living with cancer - A report on the patient experience. Toronto, Ontario, Canada: Canadian Partnership Against Cancer, 2018 January. Available from: <http://www.systemperformance.ca>.
- Cancer and Primary Care Research International Network Conference (Ca-PRI), editor 2019 May 21-23, 2019; Toronto, Ontario. Available from: <https://ca-pri.org/>.

- Cancer Care Ontario. Follow-up model of care for cancer survivors: Recommendations for the delivery of follow-up care for cancer survivors in Ontario. Toronto 2019. Available from: <https://www.cancercareontario.ca/en/content/follow-model-care-cancer-survivors-recommendations-delivery-follow-care-cancer-survivors-ontario>.
- Casillas J, Goyal A, Bryman J, Alquaddoomi F, Ganz PA, Lidington E, et al. Development of a text messaging system to improve receipt of survivorship care in adolescent and young adult survivors of childhood cancer. *Journal of Cancer Survivorship*. 2017;11(4):505-16. Available from: <https://doi.org/10.1007/s11764-017-0609-0>.
- Cavanagh BM, Wakefield CE, McLoone JK, Garvey G, Cohn RJ. Cancer survivorship services for indigenous peoples: where we stand, where to improve? A systematic review. *Journal of Cancer Survivorship*. 2016;10(2):330-41. Available from: <https://doi.org/10.1007/s11764-015-0479-2>.
- Cavers D. The experience of living with and beyond cancer with comorbid illness: A qualitative systematic review. *Cancer and Primary Care Research International Network Conference (Ca-PRI) 2018*; April 18-20; Groningen, Netherlands 2018. Available from: <https://ca-pri.org>.
- Chaput G. The survivorship care plan: a valuable tool for primary care providers? 2018. 2018;25(3):194-5. Available from: <https://doi.org/10.3747/co.25.4156>.
- Cheng KKF, Lim YTE, Koh ZM, Tam WWS. Home-based multidimensional survivorship programmes for breast cancer survivors. *The Cochrane database of systematic reviews*. 2017;8:CD011152. Available from: <https://doi.org/10.1002/14651858.CD011152.pub2>.
- Cipolletta S, Simonato C, Faccio E. The effectiveness of psychoeducational support groups for women with breast cancer and their caregivers: A mixed methods study. *Frontiers in psychology*. 2019;10:288-. Available from: <https://doi.org/10.3389/fpsyg.2019.00288>.
- College of Family Physicians of Canada. A new vision for Canada: Family Practice—The Patient's Medical Home. Mississauga, Ontario: College of Family Physicians of Canada, 2019. Available from: <https://patientsmedicalhome.ca/vision/physicians/>.
- Corbett T, Singh K, Payne L, Bradbury K, Foster C, Watson E, et al. Understanding acceptability of and engagement with Web-based interventions aiming to improve quality of life in cancer survivors: A synthesis of current research. *Psycho-oncology*. 2018;27(1):22-33. Available from: <https://doi.org/10.1002/pon.4566>.
- Cox A, Lucas G, Marcu A, Piano M, Grosvenor W, Mold F, et al. Cancer survivors' experience with telehealth: A systematic review and thematic synthesis. *J Med Internet Res*. 2017;19(1):e11. Available from: <https://doi.org/10.2196/jmir.6575>.
- Cramer H, Lauche R, Klose P, Lange S, Langhorst J, Dobos GJ. Yoga for improving health-related quality of life, mental health and cancer-related symptoms in women diagnosed with breast cancer. *The Cochrane database of systematic reviews*. 2017;1:CD010802. Available from: <https://doi.org/10.1002/14651858.CD010802.pub2>.
- Culos-Reed SN, Dew M, Shank J, Langelier DM, McDonough M. Qualitative evaluation of a community-based physical activity and yoga program for men living with prostate cancer: Survivor perspectives. *Global advances in health and medicine*. 2019;8:2164956119837487. Available from: <https://doi.org/10.1177/2164956119837487>.
- Daudt HML, van Mossel C, Dennis DL, Leitz L, Watson HC, Tanliao JJ. Survivorship care plans: a work in progress. 2014. 2014;21(3):14. Available from: <https://dx.doi.org/10.3747/co.21.1781>.
- de Boer A. The role of the general practitioner in return to work after cancer – a systematic review. *Cancer and Primary Care Research International Network Conference (Ca-PRI) 2018*; April 18-20; Groningen, Netherlands 2018. Available from: <https://ca-pri.org>.
- de Boer AG, Taskila TK, Tamminga SJ, Feuerstein M, Frings-Dresen MH, Verbeek JH. Interventions to enhance return-to-work for cancer patients. *The Cochrane database of systematic reviews*. 2015(9):CD007569. Available from: <https://doi.org/10.1002/14651858.CD007569.pub3>.
- Del Giudice ME, Grunfeld E, Harvey BJ, Pilotis E, Verma S. Primary care physicians' views of routine follow-up care of cancer survivors. *Journal of Clinical Oncology*. 2009;27(20):3338-45. Available from: <https://doi.org/10.1200/JCO.2008.20.4883>.
- Demark-Wahnefried W, Schmitz KH, Alfano CM, Bail JR, Goodwin PJ, Thomson CA, et al. Weight management and physical activity throughout the cancer care continuum. *CA Cancer J Clin*. 2018;68(1):64-89. Available from: <https://doi.org/10.3322/caac.21441>.

- Denlinger CS, Sanft T, Baker KS, Broderick G, Demark-Wahnefried W, Friedman DL, et al. Survivorship, Version 1.2019, NCCN Clinical Practice Guidelines in Oncology. 2019 March 14. Available from: <http://nccn.org>.
- Dietrich L, Smith AL, Watral A, Borgert AJ, Al-Hamadani M, Van Oosbree M, et al. Effectiveness of a survivorship program: An assessment of patients with breast cancer in a community setting. *Journal of Oncology Practice*. 2016;12(6):e688-e96. Available from: <https://doi.org/10.1200/JOP.2015.010413>.
- Dorland HF, Abma FI, Van Zon SKR, Stewart RE, Amick BC, Ranchor AV, et al. Fatigue and depressive symptoms improve but remain negatively related to work functioning over 18 months after return to work in cancer patients. *Journal of Cancer Survivorship*. 2018;12(3):371-8. Available from: <https://doi.org/10.1007/s11764-018-0676-x>.
- Duijts SF, van Egmond MP, Spelten E, van Muijen P, Anema JR, van der Beek AJ. Physical and psychosocial problems in cancer survivors beyond return to work: a systematic review. *Psycho-oncology*. 2014;23(5):481-92. Available from: <https://doi.org/10.1002/pon.3467>.
- Duijts SFA. Management of work through the seasons of cancer survivorship. *Current opinion in supportive and palliative care*. 2018;12(1):80-5. Available from: <https://doi.org/10.1097/spc.0000000000000320>.
- Edwards K, Wilkins A, McManus P. P042. Evaluation of a breast cancer survivorship programme: 7-year patient outcomes and service experience. *European Journal of Surgical Oncology*. 2019;45(5):896-7. Available from: <https://doi.org/10.1016/j.ejso.2019.01.064>.
- El-Hashimi D, Gorey KM. Yoga-specific enhancement of quality of life among women with breast cancer: Systematic review and exploratory meta-analysis of randomized controlled trials. *Journal of evidence-based integrative medicine*. 2019;24:2515690x19828325. Available from: <https://doi.org/10.1177/2515690x19828325>.
- Fallon EA, Driscoll D, Smith TS, Richardson K, Portier K. Description, characterization, and evaluation of an online social networking community: the American Cancer Society's Cancer Survivors Network®. *Journal of Cancer Survivorship*. 2018;12(5):691-701. Available from: <https://doi.org/10.1007/s11764-018-0706-8>.
- Fann JR, Ell K, Sharpe M. Integrating psychosocial care into cancer services. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2012;30(11):1178-86. Available from: <https://doi.org/10.1200/jco.2011.39.7398>.
- Fann JR, Fan MY, Unutzer J. Improving primary care for older adults with cancer and depression. *Journal of general internal medicine*. 2009;24 Suppl 2:S417-24. Available from: <https://doi.org/10.1007/s11606-009-0999-4>.
- Fassier JB, Lamort-Bouche M, Broc G, Guittard L, Peron J, Rouat S, et al. Developing a return to work intervention for breast cancer survivors with the intervention mapping protocol: Challenges and opportunities of the needs assessment. *Frontiers in public health*. 2018;6:35. Available from: <https://doi.org/10.3389/fpubh.2018.00035>.
- Ferenchick EK, Ramanuj P, Pincus HA. Depression in primary care: part 1—screening and diagnosis. *BMJ*. 2019;365:l794. Available from: <https://doi.org/10.1136/bmj.l794>.
- Fitch M, Zomer S, Lockwood G, Louzado C, Shaw Moxam R, Rahal R, et al. Experiences of adult cancer survivors in transitions. *Supportive Care in Cancer*. 2018. Available from: <https://doi.org/10.1007/s00520-018-4605-3>.
- Forbes CC, Finlay A, McIntosh M, Siddiquee S, Short CE. A systematic review of the feasibility, acceptability, and efficacy of online supportive care interventions targeting men with a history of prostate cancer. *Journal of Cancer Survivorship*. 2019;13(1):75-96. Available from: <https://doi.org/10.1007/s11764-018-0729-1>.
- Foster C, Fenlon D. Recovery and self-management support following primary cancer treatment. *British Journal Of Cancer*. 2011;105:S21. Available from: <https://doi.org/10.1038/bjc.2011.419>.
- Glaser A. National Cancer Survivorship Initiative Model of Care. National Cancer Survivor Initiative, 2010. Available from: <http://www.ncin.org.uk/>.
- Glaser KM, McDaniel DC, Hess SM, Flores TF, Rokitka DA, Reid ME. Implementing an integrative survivorship program at a comprehensive cancer center: A multimodal approach to life after cancer. *Journal of alternative and complementary medicine (New York, NY)*. 2019;25(S1):S106-s11. Available from: <https://doi.org/10.1089/acm.2018.0383>.
- Graham L, Wikman A. Toward improved survivorship: supportive care needs of esophageal cancer patients, a literature review. *Diseases of the esophagus : official journal of the International Society for Diseases of the Esophagus*. 2016;29(8):1081-9. Available from: <https://doi.org/10.1111/dote.12424>.

- Grimmett C, Corbett T, Brunet J, Shepherd J, Pinto BM, May CR, et al. Systematic review and meta-analysis of maintenance of physical activity behaviour change in cancer survivors. *The international journal of behavioral nutrition and physical activity*. 2019;16(1):37. Available from: <https://doi.org/1186/s12966-019-0787-4>.
- Grunfeld E, Julian JA, Pond G, Maunsell E, Coyle D, Folkes A, et al. Evaluating survivorship care plans: results of a randomized, clinical trial of patients with breast cancer. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2011;29(36):4755-62. Available from: <https://doi.org/10.1200/jco.2011.36.8373>.
- Gudenkauf LM, Ehlers SL. Psychosocial interventions in breast cancer survivorship care. *Breast (Edinburgh, Scotland)*. 2018;38:1-6. Available from: <https://doi.org/10.1016/j.breast.2017.11.005>.
- Haas J, Persson M, Brorsson AL, Toft EH, Olinder AL. Guided self-determination-young versus standard care in the treatment of young females with type 1 diabetes: study protocol for a multicentre randomized controlled trial. *Trials*. 2017;18(1):562-. Available from: <https://doi.org/10.1186/s13063-017-2296-6>.
- Harper GW, Lemos D, Hosek SG. Stigma reduction in adolescents and young adults newly diagnosed with HIV: findings from the Project ACCEPT intervention. *AIDS Patient Care STDS*. 2014;28(10):543-54. Available from: <https://doi.org/10.1089/apc.2013.0331>.
- Hoffman B. Working it Out. National Coalition for Cancer Survivorship, 2012. Available from: <https://www.canceradvocacy.org/>.
- Hoving JL, Broekhuizen MLA, Frings-Dresen MHW. Return to work of breast cancer survivors: a systematic review of intervention studies. *BMC Cancer*. 2009;9(1):117. Available from: <https://doi.org/10.1186/1471-2407-9-117>.
- Howell D, Hack TF, Oliver TK, Chulak T, Mayo S, Aubin M, et al. Pan-Canadian guidance on organization and structure of survivorship services and psychosocial-supportive care best practices for adult cancer survivors. Toronto, Ontario, Canada: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology, 2011 April. Available from: <https://www.capo.ca/guidelines>.
- Howell D, Keshavarz H, Esplen MJ, Hack T, Hamel M, Howes J, et al. Pan-Canadian practice guideline: Screening, assessment and management of psychosocial distress, depression and anxiety in adults with cancer. Canadian Partnership Against Cancer and the Canadian Association of Psychosocial Oncology,, 2015 July 30. Available from: <https://www.capo.ca/guidelines>.
- Howell DD. Supported self-management for cancer survivors to address long-term biopsychosocial consequences of cancer and treatment to optimize living well. *Current opinion in supportive and palliative care*. 2018;12(1):92-9. Available from: <https://doi.org/10.1097/spc.0000000000000329>.
- Huber J, Muck T, Maatz P, Keck B, Enders P, Maatouk I, et al. Face-to-face vs. online peer support groups for prostate cancer: A cross-sectional comparison study. *Journal of Cancer Survivorship*. 2018;12(1):1-9. Available from: <https://doi.org/10.1007/s11764-017-0633-0>.
- Hulett JM, Armer JM. A systematic review of spiritually based interventions and psychoneuroimmunological outcomes in breast cancer survivorship. *Integr Cancer Ther*. 2016;15(4):405-23. Available from: <https://doi.org/10.1177/1534735416636222>.
- Hunter EG, Gibson RW, Arbesman M, D'Amico M. Systematic review of occupational therapy and adult cancer rehabilitation: Part 2. Impact of multidisciplinary rehabilitation and psychosocial, sexuality, and return-to-work interventions. *The American journal of occupational therapy : official publication of the American Occupational Therapy Association*. 2017;71(2):7102100040p1-p8. Available from: <https://doi.org/10.5014/ajot.2017.023572>.
- Hydeman JA, Uwazurike OC, Adeyemi EI, Beaupin LK. Survivorship needs of adolescent and young adult cancer survivors: a concept mapping analysis. *Journal of Cancer Survivorship*. 2019;13(1):34-42. Available from: <https://doi.org/10.1007/s11764-018-0725-5>.
- International Psycho-oncology Society. International Standard of Quality Cancer Care 2014. Available from: <https://ipos-society.org/about/quality>.
- Irwin ML, Cartmel B, Harrigan M, Li F, Sanft T, Shockro L, et al. Effect of the LIVESTRONG at the YMCA exercise program on physical activity, fitness, quality of life, and fatigue in cancer survivors. *Cancer*. 2017;123(7):1249-58. Available from: <https://doi.org/10.1002/cncr.30456>.

- Ismail Y, Hendry J. Support needs of adolescents' post-cancer treatment: A systematic review. *Radiography* (London, England : 1995). 2018;24(2):175-83. Available from: <https://doi.org/10.1016/j.radi.2017.12.004>.
- Ives J. Cancer patients with mental health history have greater risk of death. 2019. Available from: <https://www.news-medical.net/news/20190307/Cancer-patients-with-mental-health-history-have-greater-risk-of-death.aspx>.
- Jain J, Qorri B, Szewczuk MR. The crucial role of primary care providers in the long-term follow-up of adult survivors of childhood cancer. *Cancer Management and Research*. 2019;Volume 11:3411-8. Available from: <https://doi.org/10.2147/cmar.S197644>.
- Khan NF, Evans J, Rose PW. A qualitative study of unmet needs and interactions with primary care among cancer survivors. *British Journal Of Cancer*. 2011;105:S46. Available from: <https://doi.org/10.1038/bjc.2011.422>.
- Kim J, Lim S, Min YH, Shin YW, Lee B, Sohn G, et al. Depression Screening Using Daily Mental-Health Ratings from a Smartphone Application for Breast Cancer Patients. *J Med Internet Res*. 2016;18(8):e216. Available from: <https://doi.org/10.2196/jmir.5598>.
- Knauf MT, Schultz IZ. Current Conceptual Models of Return to Work. In: Schultz IZ, Gatchel RJ, editors. *Handbook of return to work: From research to practice*. Boston, MA: Springer US; 2016. p. 27-51. Available from: [https://doi.org/10.1007/978-1-4899-7627-7\\_2](https://doi.org/10.1007/978-1-4899-7627-7_2).
- Kotronoulas G, Papadopoulou C, Burns-Cunningham K, Simpson M, Maguire R. A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum. *European Journal of Oncology Nursing*. 2017;29:60-70. Available from: <https://doi.org/10.1016/j.ejon.2017.05.004>.
- Krebber AMH, Buffart LM, Kleijn G, Riepma IC, de Bree R, Leemans CR, et al. Prevalence of depression in cancer patients: a meta-analysis of diagnostic interviews and self-report instruments. *Psycho-oncology*. 2014;23(2):121-30. Available from: <https://doi.org/10.1002/pon.3409>.
- Lang-Rollin I, Berberich G. *Psycho-oncology. Dialogues in clinical neuroscience*. 2018;20(1):13-22. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/29946207>.
- Lathren C, Bluth K, Campo R, Tan W, Futch W. Young adult cancer survivors' experiences with a mindful self-compassion (MSC) video-chat intervention: A qualitative analysis. *Self and identity : the journal of the International Society for Self and Identity*. 2018;17(6):646-65. Available from: <https://doi.org/10.1080/15298868.2018.1451363>.
- Leensen MCJ, Groeneveld IF, Heide Ivd, Rejda T, van Veldhoven PLJ, Berkel Sv, et al. Return to work of cancer patients after a multidisciplinary intervention including occupational counselling and physical exercise in cancer patients: a prospective study in the Netherlands. *BMJ Open*. 2017;7(6):e014746. Available from: <https://doi.org/10.1136/bmjopen-2016-014746>.
- Levin GT, Greenwood KM, Singh F, Tsoi D, Newton RU. Exercise improves physical function and mental health of brain cancer survivors: Two exploratory case studies. *Integrative Cancer Therapies*. 2015;15(2):190-6. Available from: <https://doi.org/10.1177/1534735415600068>.
- Leykin Y, Thekdi SM, Shumay DM, Munoz RF, Riba M, Dunn LB. Internet interventions for improving psychological well-being in psycho-oncology: review and recommendations. *Psycho-oncology*. 2012;21(9):1016-25. Available from: <https://doi.org/10.1002/pon.1993>.
- Li M, Macedo A, Crawford S, Bagha S, Leung YW, Zimmermann C, et al. Easier said than done: Keys to successful implementation of the Distress Assessment And Response Tool (DART) program. *Journal of Oncology Practice*. 2016;12(5):e513-e26. Available from: <https://doi.org/10.1200/jop.2015.010066>.
- Livingston PM, Craike MJ, Salmon J, Courneya KS, Gaskin CJ, Fraser SF, et al. Effects of a clinician referral and exercise program for men who have completed active treatment for prostate cancer: A multicenter cluster randomized controlled trial (ENGAGE). *Cancer*. 2015;121(15):2646-54. Available from: <https://doi.org/10.1002/cncr.29385>.
- Loprinzi CE, Prasad K, Schroeder DR, Sood A. Stress Management and Resilience Training (SMART) program to decrease stress and enhance resilience among breast cancer survivors: a pilot randomized clinical trial. *Clinical breast cancer*. 2011;11(6):364-8. Available from: <https://doi.org/10.1016/j.clbc.2011.06.008>.
- Luckett T, Britton B, Clover K, Rankin NM. Evidence for interventions to improve psychological outcomes in people with head and neck cancer: a systematic review of the literature. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*. 2011;19(7):871-81. Available from: <https://doi.org/10.1007/s00520-011-1119-7>.

- Mehnert A, Koch U. Psychological comorbidity and health-related quality of life and its association with awareness, utilization, and need for psychosocial support in a cancer register-based sample of long-term breast cancer survivors. *Journal of Psychosomatic Research*. 2008;64(4):383-91. Available from: <https://doi.org/10.1016/j.jpsychores.2007.12.005>.
- Meiklejohn JA, Mimery A, Martin JH, Bailie R, Garvey G, Walpole ET, et al. The role of the GP in follow-up cancer care: a systematic literature review. *Journal of Cancer Survivorship*. 2016;10(6):990-1011. Available from: <https://doi.org/10.1007/s11764-016-0545-4>.
- Mendes-Santos C, Weiderpass E, Santana R, Andersson G. A guided internet-delivered individually-tailored ACT-influenced cognitive behavioural intervention to improve psychosocial outcomes in breast cancer survivors (iNOVBC): Study protocol. *Internet interventions*. 2019;17:100236. Available from: <https://doi.org/10.1016/j.invent.2019.01.004>.
- Mental Health Commission of Canada. National standard of Canada for psychological health and safety in the workplace. Ottawa 2013. Available from: <https://www.mentalhealthcommission.ca/English/what-we-do/workplace/national-standard>.
- Mental Health Commission of Canada. Guidelines for recovery-oriented practice. Ottawa, Ontario: 2015. Available from: [https://www.mentalhealthcommission.ca/sites/default/files/MHCC\\_RecoveryGuidelines\\_ENG\\_0.pdf](https://www.mentalhealthcommission.ca/sites/default/files/MHCC_RecoveryGuidelines_ENG_0.pdf).
- Metcalfe R. Stratified Follow-up Pathways – Case study: Implementation of stratified follow up guidance for breast, prostate and colorectal cancer within South Yorkshire, Bassetlaw and North Derbyshire Cancer Alliance. UK: Macmillan Living With and Beyond Cancer Programme, South Yorkshire Bassetlaw and North Derbyshire Cancer Alliance, 2018 November. Available from: <http://www.northerncanceralliance.nhs.uk>.
- Miedema B. Still building the bridge! Barriers to transitioning to primary health care for cancer follow-up care. Cancer and Primary Care Research International Network Conference (Ca-PRi) 2018; April 18-20; Groningen, Netherlands 2018. Available from: <https://ca-pri.org>.
- Mishra SI, Scherer RW, Geigle PM, Berlanstein DR, Topaloglu O, Gotay CC, et al. Exercise interventions on health-related quality of life for cancer survivors. *The Cochrane database of systematic reviews*. 2012(8):Cd007566. Available from: <https://doi.org/10.1002/14651858.CD007566.pub2>.
- Mitchell AJ, Ferguson DW, Gill J, Paul J, Symonds P. Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *The Lancet Oncology*. 2013;14(8):721-32. Available from: [https://doi.org/10.1016/s1470-2045\(13\)70244-4](https://doi.org/10.1016/s1470-2045(13)70244-4).
- Mohn J, Graue M, Assmus J, Zoffmann V, Thordarson H, Peyrot M, et al. The effect of guided self-determination on self-management in persons with type 1 diabetes mellitus and HbA<sub>1c</sub> ≥64 mmol/mol: a group-based randomised controlled trial. *BMJ Open*. 2017;7(6):e013295. Available from: <https://doi.org/10.1136/bmjopen-2016-013295>.
- Mosher CE, Winger JG, Given BA, Helft PR, O'Neil BH. Mental health outcomes during colorectal cancer survivorship: a review of the literature. *Psycho-oncology*. 2016;25(11):1261-70. Available from: <https://doi.org/10.1002/pon.3954>.
- Nakash O, Levav I, Aguilar-Gaxiola S, Alonso J, Andrade LH, Angermeyer MC, et al. Comorbidity of common mental disorders with cancer and their treatment gap: findings from the World Mental Health Surveys. *Psycho-oncology*. 2014;23(1):40-51. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3992888/>.
- National Cancer Survivorship Resource Center. Moving beyond patient satisfaction: Tips to measure program impact. USA: 2013. Available from: <https://www.cancer.org/content/cancer/en/health-care-professionals/national-cancer-survivorship-resource-center/tools-for-health-care-professionals.html>.
- National Health Service (UK). NHS Improvement - Cancer - Effective follow up: Testing risk stratified pathways. Leicester, United Kingdom: NHS Improvement, 2011 May. Available from: [www.improvement.nhs.uk/cancer/survivorship](http://www.improvement.nhs.uk/cancer/survivorship).
- National Research Council. From cancer patient to cancer survivor: Lost in transition. Hewitt M, Greenfield S, Stovall E, editors. Washington, DC: The National Academies Press; 2006. 534 p. Available from: <https://doi.org/10.17226/11468>.
- Nekhlyudov L. Developing a framework for measuring quality of cancer survivorship care. Cancer and Primary Care Research International Network Conference (Ca-PRi) 2018; April 18-20; Groningen, Netherlands 2018. Available from: <https://ca-pri.org>.

- Nekhlyudov L, Ganz PA, Arora NK, Rowland JH. Going Beyond Being Lost in Transition: A Decade of Progress in Cancer Survivorship. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2017;35(18):1978-81. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/28437163>  
<https://www.ncbi.nlm.nih.gov/pmc/PMC5676953/>.
- Park EM, Rosenstein DL. Depression in adolescents and young adults with cancer. *Dialogues in clinical neuroscience*. 2015;17(2):171-80. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4518700/>.
- Paterson C, Robertson A, Smith A, Nabi G. Identifying the unmet supportive care needs of men living with and beyond prostate cancer: A systematic review. *European Journal of Oncology Nursing*. 2015;19(4):405-18. Available from: <https://doi.org/10.1016/j.ejon.2014.12.007>.
- Polley MJ, Jolliffe R, Boxell E, Zollman C, Jackson S, Seers H. Using a whole person approach to support people with cancer: A longitudinal, mixed-methods service evaluation. *Integrative Cancer Therapies*. 2016;15(4):435-45. Available from: <https://doi.org/10.1177/1534735416632060>.
- Post KE, Flanagan J. Web based survivorship interventions for women with breast cancer: An integrative review. *European journal of oncology nursing : the official journal of European Oncology Nursing Society*. 2016;25:90-9. Available from: <https://doi.org/10.1016/j.ejon.2016.10.004>.
- Rabin C, Simpson N, Morrow K, Pinto B. Behavioral and psychosocial program needs of young adult cancer survivors. *Qualitative Health Research*. 2010;21(6):796-806. Available from: <https://doi.org/10.1177/1049732310380060>.
- Rajotte EJ, Yi JC, Baker KS, Gregerson L, Leiserowitz A, Syrjala KL. Community-based exercise program effectiveness and safety for cancer survivors. *Journal of Cancer Survivorship*. 2012;6(2):219-28. Available from: <https://doi.org/10.1007/s11764-011-0213-7>.
- Ramanuj P, Ferencik EK, Pincus HA. Depression in primary care: part 2—management. *BMJ*. 2019;365:l835. Available from: <https://doi.org/10.1136/bmj.l835>.
- Raphael D, Frey R, Gott M. Psychosocial distress in haematological cancer survivors: An integrative review. *European journal of cancer care*. 2017;26(6). Available from: <https://doi.org/10.1111/ecc.12640>.
- Rasmussen LA. Activity in general practice preceding a diagnosis of cancer recurrence. *Cancer and Primary Care Research International Network Conference (Ca-PRI) 2018; April 18-20; Groningen, Netherlands 2018*. Available from: <https://ca-pri.org>.
- Recklitis CJ, Syrjala KL. Provision of integrated psychosocial services for cancer survivors post-treatment. *The Lancet Oncology*. 2017;18(1):e39-e50. Available from: [https://doi.org/10.1016/s1470-2045\(16\)30659-3](https://doi.org/10.1016/s1470-2045(16)30659-3).
- Richards M, Corner J, Maher J. The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. *British journal of cancer*. 2011;105 Suppl 1(Suppl 1):S1-S4. Available from: <https://doi.org/10.1038/bjc.2011.416>.
- Robinson P J RJT. Behavioral consultation and primary care: the “why now?” and “how? Behavioral consultation and primary care: a guide to integrating services: Springer International Publishing; 2016. Available from: <https://www.springer.com/gp/book/9783319139531>.
- Rodin G, Lo C, Rydall A, Shnall J, Malfitano C, Chiu A, et al. Managing Cancer and Living Meaningfully (CALM): A randomized controlled trial of a psychological intervention for patients with advanced cancer. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2018;36(23):2422-32. Available from: <https://doi.org/10.1200/JCO.2017.77.1097>.
- Roland KB, Rodriguez JL, Patterson JR, Trivers KF. A literature review of the social and psychological needs of ovarian cancer survivors. *Psycho-oncology*. 2013;22(11):2408-18. Available from: <https://doi.org/10.1002/pon.3322>.
- Rushton M, Morash R, Larocque G, Liska C, Stoica L, DeGrasse C, et al. Wellness Beyond Cancer Program: building an effective survivorship program. *Current oncology (Toronto, Ont)*. 2015;22(6):e419-e34. Available from: <https://doi.org/10.3747/co.22.2786>.
- Salsman JM, Pustejovsky JE, Jim HSL, Munoz AR, Merluzzi TV, George L, et al. A meta-analytic approach to examining the correlation between religion/spirituality and mental health in cancer. *Cancer*. 2015;121(21):3769-78. Available from: <https://doi.org/10.1002/cncr.29350>.



- Sandel SL, Judge JO, Landry N, Faria L, Ouellette R, Majczak M. Dance and movement program improves quality-of-life measures in breast cancer survivors. *Cancer nursing*. 2005;28(4):301-9. Available from: <https://insights.ovid.com/pubmed?pmid=16046894>.
- Saracino RM, Nelson CJ. Identification and treatment of depressive disorders in older adults with cancer. *J Geriatr Oncol*. 2019. Available from: <https://doi.org/10.1016/j.jgo.2019.02.005>.
- Schepisi G, De Padova S, De Lisi D, Casadei C, Meggiolaro E, Ruffilli F, et al. Psychosocial issues in long-term survivors of testicular cancer. *Frontiers in endocrinology*. 2019;10:113. Available from: <https://doi.org/10.3389/fendo.2019.00113>.
- Schreiber JA, Brockopp DY. Twenty-five years later--what do we know about religion/spirituality and psychological well-being among breast cancer survivors? A systematic review. *Journal of cancer survivorship : research and practice*. 2012;6(1):82-94. Available from: <https://doi.org/10.1007/s11764-011-0193-7>.
- Schultz IZ, Gatchel RJ. Handbook of return to work. Schultz IZ, Gatchel RJ, editors. Boston, MA: Springer US; 2016 2016//. 27-51 p.
- Seers H, Griffiths M, Churchward S, Samuel R, Naidoo M, French H, et al., editors. Evaluation of Penny Brohn UK's national programme of 'Living Well With and Beyond Cancer'services. National Cancer Research Institute Conference,; 2018 November 4-6; Glasgow,. Available from: <https://www.pennybrohn.org.uk>.
- Smith A, Sharpe L, Thewes B, Turner J, Gilchrist J, Fardell JE, et al. Medical, demographic and psychological correlates of fear of cancer recurrence (FCR) morbidity in breast, colorectal and melanoma cancer survivors with probable clinically significant FCR seeking psychological treatment through the ConquerFear study. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*. 2018;26(12):4207-16. Available from: <https://doi.org/10.1007/s00520-018-4294-y>.
- Smith HR. Depression in cancer patients: Pathogenesis, implications and treatment (Review). *Oncol Lett*. 2015;9(4):1509-14. Available from: <https://doi.org/10.3892/ol.2015.2944>.
- Stanton AL. Psychosocial concerns and interventions for cancer survivors. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2006;24(32):5132-7. Available from: <https://doi.org/10.1200/jco.2006.06.8775>.
- Stergiou-Kita M, Grigorovich A, Tseung V, Milosevic E, Hebert D, Phan S, et al. Qualitative meta-synthesis of survivors' work experiences and the development of strategies to facilitate return to work. *Journal of cancer survivorship : research and practice*. 2014;8(4):657-70. Available from: <https://doi.org/10.1007/s11764-014-0377-z>.
- Stergiou-Kita M, Pritlove C, van Eerd D, Holness LD, Kirsh B, Duncan A, et al. The provision of workplace accommodations following cancer: survivor, provider, and employer perspectives. *Journal of cancer survivorship : research and practice*. 2016;10(3):489-504. Available from: <https://doi.org/10.1007/s11764-015-0492-5>.
- Stone DS, Ganz PA, Pavlish C, Robbins WA. Young adult cancer survivors and work: a systematic review. *Journal of cancer survivorship : research and practice*. 2017;11(6):765-81. Available from: <https://doi.org/10.1007/s11764-017-0614-3>.
- Storey L, Fern LA, Martins A, Wells M, Bennister L, Gerrand C, et al. A critical review of the impact of sarcoma on psychosocial wellbeing. *Sarcoma*. 2019;2019:9730867. Available from: <https://doi.org/10.1155/2019/9730867>.
- Stroke Association. Stroke Recovery Service - The value of our services. London, United Kingdom: Stroke Association (UK), 2018 August. Available from: <http://stroke.org.uk>.
- Strong V, Waters R, Hibberd C, Murray G, Wall L, Walker J, et al. Management of depression for people with cancer (SMaRT oncology 1): a randomised trial. *Lancet (London, England)*. 2008;372(9632):40-8. Available from: [https://doi.org/10.1016/s0140-6736\(08\)60991-5](https://doi.org/10.1016/s0140-6736(08)60991-5).
- Sun Y, Shigaki CL, Armer JM. Return to work among breast cancer survivors: A literature review. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*. 2017;25(3):709-18. Available from: <https://doi.org/10.1007/s00520-016-3446-1>.
- Sunderland K, Mishkin, Wendy, Peer Leadership Group, Mental Health Commission of Canada,. Guidelines for the practice and training of peer support. Calgary2013. Available from: [https://www.mentalhealthcommission.ca/sites/default/files/peer\\_support\\_guidelines.pdf](https://www.mentalhealthcommission.ca/sites/default/files/peer_support_guidelines.pdf).

- Tan SY, Turner J, Kerin-Ayres K, Butler S, Deguchi C, Khatri S, et al. Health concerns of cancer survivors after primary anti-cancer treatment. *Supportive Care in Cancer*. 2019. Available from: <https://doi.org/10.1007/s00520-019-04664-w>.
- Turner RR, Steed L, Quirk H, Greasley RU, Saxton JM, Taylor SJ, et al. Interventions for promoting habitual exercise in people living with and beyond cancer. *The Cochrane database of systematic reviews*. 2018;9:CD010192. Available from: <https://doi.org/10.1002/14651858.CD010192.pub3>.
- Urquhart R. Survivorship care plans: Discrepancies between what RCTs assess and what stakeholders expect from their use. *Cancer and Primary Care Research International Network Conference (Ca-PRI) 2018*; April 18-20; Groningen, Netherlands 2018. Available from: <https://ca-pri.org>.
- van Maarschalkerweerd PEA, Schaapveld M, Paalman CH, Aaronson NK, Duijts SFA. Changes in employment status, barriers to, and facilitators of (return to) work in breast cancer survivors 5-10 years after diagnosis. *Disability and rehabilitation*. 2019;1-7. Available from: <https://doi.org/10.1080/09638288.2019.1583779>.
- Vehling S, Philipp R. Existential distress and meaning-focused interventions in cancer survivorship. *Current opinion in supportive and palliative care*. 2018;12(1):46-51. Available from: <https://doi.org/10.1097/spc.0000000000000324>.
- Weinstein AG, Henrich CC, Armstrong GT, Stratton KL, King TZ, Leisenring WM, et al. Roles of positive psychological outcomes in future health perception and mental health problems: A report from the Childhood Cancer Survivor Study. *Psycho-Oncology*. 2018;27(12):2754-60. Available from: <https://doi.org/10.1002/pon.4881>.
- Wieldraaijer T, Duineveld L, Donkervoort S, Busschers W, Weert Hv, Wind J. Colorectal cancer patients' preferences for type of caregiver during survivorship care. *Cancer and Primary Care Research International Network Conference (Ca-PRI) 2018*; April 18-20; Groningen, Netherlands 2018. Available from: <https://ca-pri.org>.
- Willems RA, Mesters I, Lechner L, Kanera IM, Bolman CAW. Long-term effectiveness and moderators of a web-based tailored intervention for cancer survivors on social and emotional functioning, depression, and fatigue: randomized controlled trial. *Journal of Cancer Survivorship*. 2017;11(6):691-703. Available from: <https://doi.org/10.1007/s11764-017-0625-0>.
- Wollersheim B, van Weert HCPM, van Asselt KM, van der Poel HG, Aaronson NK, van de Poll-Franse LV, et al. Prostate cancer follow-up care in secondary and primary health care (prospec study): Study protocol for a randomised controlled trial. *Cancer and Primary Care Research International Network Conference (Ca-PRI) 2018*; April 18-20; Groningen, The Netherlands 2018. Available from: <https://ca-pri.org>.
- Wolters MDJ, Leensen MCJ, Groeneveld IF, Frings-Dresen MHW, De Boer AGEM. Predictors for earlier return to work of cancer patients. *Journal of Cancer Survivorship*. 2018;12(2):169-77. Available from: <https://doi.org/10.1007/s11764-017-0655-7>.
- Wong JN, McAuley E, Trinh L. Physical activity programming and counseling preferences among cancer survivors: a systematic review. *The international journal of behavioral nutrition and physical activity*. 2018;15(1):48. Available from: <https://doi.org/10.1186/s12966-018-0680-6>.
- Wright D. An exploratory study of the value and impact of the Stroke Association's Stroke Recovery Service to stroke survivors and carers. United Kingdom: Merle Wright Consulting Limited, 2016 April. Available from: <http://stroke.org.uk>.
- Wu HS, Harden JK. Symptom burden and quality of life in survivorship: a review of the literature. *Cancer nursing*. 2015;38(1):E29-54. Available from: <https://doi.org/10.1097/ncc.000000000000135>.
- Zafar A. Cancer patients treated for mental health conditions have greater risk of dying, study finds. 2019 March 28. Available from: <https://www.cbc.ca/news/health/cancer-patients-mental-health-study-1.5072439>.
- Zainal NZ, Booth S, Huppert FA. The efficacy of mindfulness-based stress reduction on mental health of breast cancer patients: a meta-analysis. *Psycho-oncology*. 2013;22(7):1457-65. Available from: <https://doi.org/10.1002/pon.3171>.
- Zebrack B, Isaacson S. Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2012;30(11):1221-6. Available from: <https://doi.org/10.1200/jco.2011.39.5467>.
- Zhang J, Xu R, Wang B, Wang J. Effects of mindfulness-based therapy for patients with breast cancer: A systematic review and meta-analysis. *Complementary therapies in medicine*. 2016;26:1-10. Available from: <https://doi.org/10.1016/j.ctim.2016.02.012>.

- Zhao Y, Brettle A, Qiu L. The effectiveness of shared care in cancer survivors-a systematic review. *International journal of integrated care*. 2018;18(4):2. Available from: <https://doi.org/10.5334/ijic.3954>.
- Zoffmann V, Vistisen D, Due-Christensen M. Flexible guided self-determination intervention for younger adults with poorly controlled Type 1 diabetes, decreased HbA1c and psychosocial distress in women but not in men: a real-life RCT. *Diabetic medicine : a journal of the British Diabetic Association*. 2015;32(9):1239-46. Available from: <https://doi.org/10.1111/dme.12698>.