

Access to Oncology Physical Rehabilitation Services in British Columbia

by

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Abstract

Background

Cancer survivors report unique health complications associated with their treatment. Common symptoms include pain, compromised physical functioning, and lymphedema. Although these complications are highly responsive to physical therapy, many cancer survivors do not receive adequate physical therapy care. Furthermore, the delivery of physical therapy services for cancer survivors in British Columbia (BC) has not yet been investigated, warranting an inquiry specific to BC.

Purpose:

To develop an accurate description of the physical therapy services and programs currently accessible to oncology patients within BC's public health care system.

Methods:

A standardized survey was used to investigate the provision of physical therapy to cancer survivors across BC. Public health care sites offering physical therapy services were identified through a comprehensive list of BC hospitals and out-patient health centres. Public practice health care professionals responsible for overseeing physical therapy at each site were requested to complete a survey regarding the physical therapy care provided to cancer survivors at their respective location.

Results:

Of the 98 sites contacted, surveys were collected for 92 for an overall response rate of 94%. Seventy-one (77%) of sites offered physical therapy to oncology patients, and two (2%) reported having an oncology-specific rehabilitation program, both of which were exclusive to breast cancer survivors and located in the lower mainland (Vancouver and Surrey). Thirty-one (44% of) participants agreed that the services currently being offered at their site were meeting

the needs of their patients, 15 (21%) did not consider current services to be adequately meeting the needs of their oncology population, and 25 (35%) were unsure. The most common reasons for not meeting patient needs was lack of funding (83%), lack of professionals experienced in oncology rehabilitation (73%), and lack of resources (e.g., equipment) (70%).

Conclusion:

In BC, only two public health care sites deliver oncology-specific rehabilitation programs. The remaining sites offer services to oncology patients based on need. A minority of sites report meeting patient rehabilitation needs, with primary barriers being lack of funding, resources, and specialized health care professionals.

Lay Summary

The purpose of this study was to acquire information regarding publicly funded physiotherapy services available to cancer survivors in BC. The project used a standardized survey to determine the delivery of physiotherapy services for cancer survivors within the public practice health-care system. The survey was distributed to public practice health-care professionals responsible for overseeing physiotherapy services at health-care sites throughout BC, and inquired about the physiotherapy services available at their specific site.

The response rate was 94%. Seventy-seven percent of sites offered physiotherapy to oncology patients, and two percent reported having cancer-specific rehabilitation programs. Forty-four percent of sites considered current services to be meeting the needs of their patients, twenty-one percent did not, and thirty-five percent were unsure. The most common reasons for not meeting patient needs was lack of funding (83%), lack of specialized health-care professionals (73%), and lack of resources (e.g., equipment) (70%).

Preface

The design and implementation of this research project is my original work in consultation with the members of my thesis committee, Dr. K Campbell, Dr. D McKenzie, and Dr. P Camp.

All chapters (1-4) were written by me. After each chapter was completed, my thesis supervisor, Dr. Kristin Campbell provided feedback and revisions. This feedback was then incorporated into the final version of each chapter.

The survey used in this study was developed by myself, with input and revisions from Dr. Kristin Campbell, and knowledge broker Allison Hoens. All participants were identified and contacted by me. All web-based surveys were distributed and collected by myself. In cases where participants preferred to complete the survey via telephone, phone calls and survey administration were conducted by me. All survey analysis was conducted by myself. The protocol for analyzing education materials was developed by me. All education materials were analyzed by me, as well as independent reviewer, A. Akl. I was responsible for compiling, organizing, and storing all survey and education material data.

Results from this research project were compiled into an abstract, which was submitted and accepted for presentation at the Canadian Cancer Research Conference 2017. This abstract was written by me, with revisions given by Dr. K Campbell, Dr. D McKenzie, and B. Rafn.

Ethics approval was granted from The University of British Columbia Clinical Research Ethics Board prior to study commencement. The ethics certificate number granted for the Access to Oncology Physical Rehabilitation Services for Cancer Survivors in British Columbia: H16-01308.

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List of Abbreviations

ACS- American Cancer Society
BC- British Columbia
BCCA – BC Cancer Agency
CARF- Commission on the Accreditation of Rehabilitation Facilities
CPG- Clinical Practice Guidelines
FIM- Functional Independence Measure
HRQOL – Health related quality of life
IOM – Institute of Medicine
NIH- National Institute of Health
PABC-Physiotherapy Association of British Columbia
ROM- Range of Motion
SAM- Suitability Assessment of Materials
WHO – World Health Organization

Acknowledgements

I would like to acknowledge the contributions of my committee members, Dr. K Campbell, Dr. D McKenzie, and Dr. P Camp in the development and implementation of this thesis project. Each member contributed critically to various aspects of this project, and their guidance was immensely appreciated.

Dedication

To my mom, Beverly Grace.

Chapter 1: Introduction

1.1. Cancer Incidence in Canada

Cancer is currently the leading cause of mortality in Canada, responsible for approximately 30% of deaths nationwide.^{1,2} Furthermore, the number of individuals affected by the disease has steadily increased in recent years.² Current estimates suggest that nearly half of all Canadians will receive a cancer diagnosis within their lifetime, and approximately one quarter of the population is expected to succumb to the disease.^{1,2} However, considerable progress has been made in the field of oncology research within recent years. Cancer-related mortality has been consistently decreasing over the past two decades due to advancements in both diagnostic and treatment methods.¹ The current five-year relative survival rate for adults diagnosed with cancer in Canada is 60%, making coping with cancer survival an increasingly common phenomenon.^{1,2}

The Canadian Cancer Society defines “cancer survivor” as any living individual who has received a cancer diagnosis.¹ It is estimated that there are currently 810,045 cancer survivors in Canada, and this number is expected to increase as a result of a rapidly aging population. Current data indicates that the number of Canadians aged 65+ is expected to rise from 4.2 million to 9.4 million by 2032.^{1,2} As the Canadian population continues to age, it is anticipated that the number of individuals living beyond a cancer diagnosis will increase dramatically.^{1,2} Although many survivors recover thoroughly from treatment, individuals living beyond a cancer diagnosis often face a unique set of challenges as a result of their illness.³⁻⁷ As the number of individuals affected by the long-term health implications of cancer treatment rises, so will the need for effective supportive care strategies.⁷⁻⁹

1.2. Background

1.2.1. Long-term Health Complications

Although the cancer survivorship population is highly heterogeneous, a wide body of research has shown that survivors of all ages and cancer types frequently experience numerous chronic complications that can be disabling and complex.⁵⁻¹¹ Common adverse consequence of cancer treatment include physical impairments, such as pain, fatigue, nausea and vomiting, dyspnea, decreased bone density, muscle atrophy and sarcopenia, compromised cardiovascular function, ataxia, weakness, neuropathy, and mobility impairments.³⁻⁵ Psychological concerns, including depression, anxiety, reduced cognitive functioning and psychosocial difficulties are also frequently reported.¹¹⁻¹³ The result is well-documented reductions in quality of life (QOL), physical function, productivity and participation in daily living activities.^{3,9,10} While supportive care services offer support in managing these common side effects of cancer treatment, repeated concerns have been raised regarding the failure to address physical function in cancer survivors.¹⁴⁻¹⁷

In 2006, The Institute of Medicine (IOM) developed a specialized committee to investigate the various medical and psychosocial concerns faced by cancer survivors and provide recommendations for mitigating disease-related complications and improving health-related quality of life (HRQOL).¹⁷ Following examination, the IOM proposed four primary components of cancer survivorship care: 1) prevention and detection of new cancers and recurrent cancer; 2) surveillance for cancer spread, recurrence, or second cancers; 3) intervention for consequences of cancer and its treatment (e.g., medical problems such as lymphedema and sexual dysfunction, symptoms including pain and fatigue, psychological distress experienced by cancer survivors and their caregivers, and concerns related to employment and insurance); and 4) coordination

between specialists and primary care providers to ensure that all of the survivor's health needs are met (e.g., health promotion, immunizations, screening for both cancer and noncancerous conditions, and the care of concurrent conditions). Further statements by the IOM emphasized the importance of a patient-centered approach to survivorship by encouraging positive health behaviors while providing educational and support resources that appropriately reflect individual survivors' health status.¹⁷ Although each survivors' cancer experience is unique, evidence has consistently shown that post-treatment rehabilitation care can significantly improve physical functioning and HRQOL in survivors regardless of age, cancer type, or tumor stage.^{9,18-22}

1.2.2. The Role of Physical Rehabilitation

The World Health Organization (WHO) defines rehabilitation as a process aimed at enabling patients to reach and maintain optimal physical, intellectual, psychological, social, and spiritual levels of functioning.²³ Physical rehabilitation specifically can be defined as a medical specialty concerned with the diagnosis, evaluation, and management of physical impairments and disabilities.²⁴ Although numerous definitions have been suggested, a common consensus is that oncology rehabilitation can be defined as a process by which health care professionals treat cancer survivors' physical, psychological and cognitive impairments in attempt to maintain or restore functionality, reduce symptom burden, and maximize HRQOL.²⁵ However, for the purposes of this document, the term "oncology rehabilitation" is being used to denote specifically physical rehabilitation, namely interventions focused on physical impairments.

Many of the physical impairments reported by cancer survivors have shown to be responsive to physical rehabilitation.^{9,19-22} Studies have demonstrated oncology rehabilitation to be effective in improving numerous physical and functional outcomes in cancer survivors of various ages and tumor types, as well as improving HRQOL.^{9,19-22} Furthermore, research has

suggested that oncology rehabilitation may be effective in reducing both direct and indirect health care costs, including those resulting from lost work, disability, and early retirement.²⁶

1.3. Evidence for Oncology Rehabilitation

The first study to establish the importance of physical rehabilitation services in an oncology setting was a study by Lehmann et al. published in 1978.^{25,27}

In this prospective, descriptive study, physiatry residents conducted physical examinations and assessed the physical function concerns and rehabilitation needs of 805 cancer survivors at four different hospitals across the United States.²⁷ Results indicated that 35% of the study population had general weakness, 30% had difficulties with activities of daily living, and 25% had ambulatory impairments. The authors found that a considerable number of cancer survivors experienced coexisting physical and psychological concerns, many of which could be managed and attenuated with an appropriate rehabilitation intervention. As a result, Lehmann et al. concluded physical rehabilitation programming should be highly prioritized in oncology treatment.²⁷

1.3.1. In-Patient Setting

There is now a growing body of research literature to support the early work by Lehmann et al. In the in-patient hospital-based setting, Yoshioka et al. conducted a retrospective study observing the effects of in-patient physical rehabilitation on the physical functioning of 301 terminally ill cancer survivors in Japan in 1994.²⁸ Yoshioka et al. studied a consecutive series of 301 terminally ill cancer patients who had been provided with rehabilitation under the care of a physical therapist within the 6 months prior to their death. Rehabilitation procedures consisted of range of motion, therapeutic exercises, and pneumatic compression, as well as training for

activities of daily living, such as bathing and swallowing. Yoshioka et al. analyzed the efficacy of such rehabilitation procedures by evaluating patients' Barthel mobility index scores, which had been administered by health care providers to evaluate patient progress throughout the six-month rehabilitation program. Significant improvements in Barthel mobility index scores were identified, with a mean score change from 12.4 to 19.9 (maximum score of 47; higher score indicating better mobility). Furthermore, questionnaires completed by patients' primary care providers found that 46 participants (15%) were able to return home due to improvements in their ability to perform daily activities.²⁸

These findings are echoed in a retrospective study by Marciniak et al. published in 1996 which investigated the functional capacity of 159 cancer survivors admitted to an in-patient rehabilitation program due to a physical impairment as a result of their cancer diagnosis between 1989 and 1991.²⁰ Rehabilitation efficacy was assessed by reviewing patients changes in functional status between admission and discharge, as measured by the motor score of the Functional Independence Measure (FIM). Repeated measures analysis of variance was then conducted to establish the significance of functional gains for the entire sample size. Marciniak et al. found statistically significant improvement in FIM scores between admission (mean=42.9), and discharge (mean =56.0, $p<0.001$) (maximum score 100 points, higher score indicating higher functional capacity).²⁰

1.3.2. Out-Patient Setting

In the out-patient setting, Swenson et al. conducted a prospective study (n=115) investigating the effects of a six-month rehabilitation program designed to increase endurance, strength, and flexibility and decrease cancer-related side effects in Minneapolis, Minnesota.²⁹ The program was supervised by a physical therapist and tailored to participants' individual needs. Participants

were evaluated twice by a physical therapist, and were referred to either 1 hour individual or 90-minute group therapy sessions depending on their functional status and need for physical assistance. Functional status, measured by six-minute walk test, time spent on treadmill to exhaustion and grip strength, and self-reported symptoms, including bodily pain, symptom interference, mood, fatigue and general health, were measured at baseline, 8 weeks, and at six-months. Significant improvements were observed for six-minute walk test (+186.4 feet, +.35 mph, $p < .0001$), treadmill time (+3.5 minutes), symptom severity (-.8, $p < .0001$), symptom interference with daily life (-1.6, $p < .0001$), fatigue (-1.3, $p < .003$), dyspnea (-1.1, $p < .007$), and mood (+1.1, $p < .004$).²⁹ These results indicate that individualized rehabilitation programs targeting strength and conditioning may benefit cancer out-patient survivors of various diagnoses.²⁹

1.3.3. Systematic Reviews

This body of literature has now been summarized in a systematic review conducted by Mewes et al. which in 2012 investigated the efficacy of multidimensional oncology rehabilitation interventions on improving health-related outcomes in cancer survivors of varying types, including interventions delivered in both in-patient and/or out-patient settings.²⁶ The systematic review included 16 studies, specifically 11 randomized controlled trials, 3 pre-test post-test studies, one quasi-experiment study and one longitudinal study. All of the rehabilitation interventions included a physical exercise component in combination with psychological education. Sample sizes ranged from 21-658 participants, and included survivors of various types of cancer. Interventions lasted between 4 and 15 weeks. The most frequently reported outcome measures included physical functioning and mobility, muscular strength, cardiovascular fitness, social functioning, pain, fatigue, and HRQOL.²⁶

Fourteen studies reported statistically significant and clinically relevant benefits in at least one of the reported outcome measures. Improvements in outcomes relating to fatigue, functional capacity, muscular strength, flexibility, and energy levels were the most frequently reported. While variable, no significant improvements in HRQOL and emotional, cognitive, psychological and psychosocial outcome measures were reported. Of the 16 studies evaluated, five were restricted to breast cancer survivors and in 11 studies that aimed to include survivors of any cancer type, the majority of participants were breast cancer survivors.²⁶ Although this pattern limits the generalizability of results in relation to other cancer populations, it provides compelling evidence of the effectiveness of multidimensional rehabilitation programs in breast cancer survivors.

Aside from interventions focused on physical function in the context of rehabilitation settings led by rehabilitation professionals, such as physical therapists, occupational therapists and physiatrists, there is a large body of literature regarding the role of aerobic and resistance exercise on functional status in cancer survivors. There are three recent systematic reviews on exercise interventions in cancer survivors, which each report on different effects physical exercise has on various aspects of survivors' functional capacity.^{22,30,31}

In 2009, Spence et al. conducted a systematic review of the effects of exercise on physical function by summarizing the results of ten post-treatment exercise intervention studies for cancer survivors of various diagnoses.²² Six interventions incorporated only aerobic exercise, while four included both aerobic and resistance activities. Intervention length varied significantly, ranging from two weeks to six months, exercise frequency ranged from 2-5 days per week, and exercise sessions ranged from 30-90 minutes in duration. Spence et al. found that exercise had positive benefits on walking speed, dynamic agility, peak jumping power, and muscular strength

in breast cancer survivors' post-treatment. Improvements in time to exhaustion, resting heart rate, physical activity level, and maximal oxygen consumption ($\text{VO}_{2\text{max}}$ or $\text{VO}_{2\text{peak}}$), a well-established marker of cardiorespiratory function, were also observed in a variety of cancer survivors.²²

In 2010, Speck et al. conducted a comprehensive review of 66 high quality control trials investigating the health outcomes associated with exercise interventions in cancer survivors of various types.³⁰ The review included exercise interventions conducted both during and post-treatment, which typically ranged from moderate to vigorous intensity activity, 3-5 times per week, averaging between 30-45 minutes per session. Statistically significant improvements were observed for upper body strength, lower body strength, body composition, and functional quality of life, with the majority of studies also reporting significant benefits relating to flexibility, pain, lymphedema, and overall QOL. Similar improvements were reported for interventions conducted both during and post-treatment.³⁰

The ability of exercise to improve aerobic capacity in cancer survivors was explored further by Brown et al.³¹ A 2012 meta-analysis conducted by Brown et al. reported that exercise interventions administered during cancer treatment significantly improved $\text{VO}_{2\text{peak}}$ by $1.21 \cdot \text{ml} \cdot \text{kg}^{-1} \cdot \text{min}^{-1}$ (95% CI: $.50$ - $1.92 \text{ ml} \cdot \text{kg}^{-1} \cdot \text{min}^{-1}$) in survivors of various cancer types. It is noteworthy that improved cardiorespiratory fitness may offer clinical benefits to cancer survivors. Evidence suggests that a decrease in $\text{VO}_{2\text{peak}}$ is a common result of cancer treatment, and is associated with a higher all-cause mortality rate in cancer populations.^{32,33}

1.4. Recommendations for Oncology Rehabilitation

The Canadian Cancer Society, The American Society of Clinical Oncology and The American Cancer Society (ACS) have recognized the importance of physical rehabilitation in

helping survivors regain strength, physical function, and independence that they may have lost due to cancer and/or its associated treatment.³⁴ In 2014, The Commission on the Accreditation of Rehabilitation Facilities (CARF) formed an International Standards Advisory Committee to develop a set of guidelines identifying specifically oncology rehabilitation practices.³⁵ The advisory committee consisted of cancer survivors, family members, oncology rehabilitation specialists, health care providers, researchers, and administrators from the National Institute of Cancer at the National Institute of Health and the ACS. Advisory committee members convened for a three-day workshop to produce a set of standards for oncology rehabilitation aimed at improving and maintaining effective oncology services and programs. These guidelines were then subject to two comprehensive reviews before being finalized.³⁵

The CARF advocates that an ideal physical rehabilitation program should consist of a comprehensive program focused on strategies to optimize outcomes throughout the entire cancer trajectory, with the ultimate goal of increasing the patient's functional status to the highest possible level within their personal limitations. The CARF recommendations further emphasize the importance of a comprehensive, holistic approach to oncology rehabilitation programming, where patients' unique rehabilitation needs are identified and treated on an individual basis by a multidisciplinary team of health care professionals. This includes addressing pre-existing and treatment related comorbidities, as well as implementing appropriate preventative strategies when necessary. Comprehensive rehabilitation interventions should be multifaceted and incorporate a variety of evidence-based, patient-centered practices, including education and self-management strategies to optimize patients' functional capacity and HRQOL.³⁵ Researchers McNeely et al. suggest that guidelines developed by CARF may serve to inform the development of oncology rehabilitation services and programs throughout Canada.³⁶

1.5. Role of Physical Therapy

Health professionals tasked with delivering oncology rehabilitation care frequently include physical therapists, occupational therapists, social workers, psychologists, clinical counsellors, and physiatrists.^{25,37} Of the above-mentioned health care professionals, physical therapists and physiatrists (i.e. specialized health care professionals trained in redeveloping mobility through the identification and treatment of musculoskeletal and neurological impairments) are frequently considered to be the most knowledgeable in the development and delivery of appropriate physical rehabilitation interventions.²⁵

Physical therapy aims to optimize patients' functional capacity by improving strength and mobility through the use of therapeutic exercise, manual therapy, physical modalities and education.^{38,39} Although physical therapy frequently employs a symptom-oriented approach, physical rehabilitation strategies aimed at preventing further impairments have become increasingly common in recent years.⁴⁰ Given the range of benefits associated with oncology rehabilitation, comprehensive physical rehabilitation programming is widely considered a crucial component of standard cancer care.^{25,41,42}

Despite evidence indicating the efficacy of oncology rehabilitation, research has suggested that cancer survivors are not always referred to appropriate physical rehabilitation services.⁴³ In 2009, Cheville et al. conducted a study investigating the degree of concordance between patient reported physical impairments and their documentation within oncology-generated medical records.¹⁶ The authors administered a 27-item questionnaire inquiring about cancer related functional concerns to 244 consecutive cancer survivors undergoing outpatient treatment in Rochester, Minnesota. Approximately 45% of participants were breast cancer survivors, however, the study was not limited to any specific type of cancer diagnosis. Electronic medical records were systematically reviewed for documentation by physicians, fellows, or nurse

practitioners of items identified in the questionnaire. Eighty-three percent of participants indicated at least one cancer-related functional side effect, with balance and ambulatory concerns being the most highly prevalent, identified by 19.4% and 23.9% of participants, respectively. However, only 6% of functional concerns were recorded by clinicians in the patient medical records. It was noted that functional limitations were significantly less likely to be documented in comparison to other common cancer-related side effects such as nausea or fatigue. Furthermore, only two participants were referred to rehabilitation specialists and neither of these referrals was generated in response to functional limitations. These findings indicate that while many cancer survivors experience functional impairments as a result of their diagnosis, these concerns often remain under-recognized and under-treated by health care professionals.¹⁶

1.6. Role of Target Patient Education Materials

In the absence of available programming or to augment existing programs, a commonly used tool is patient education materials.^{44,45} Patient education can be defined as a process of influencing behavior to generate improvements in the attitudes, knowledge, and skills necessary to maintain and enhance health.^{44,45} The primary objective of patient education is to provide clinical populations such as cancer survivors with the knowledge necessary to enhance their ability to cope with illness.^{46,47} As a result, effective cancer educational programming should aim to provide informative, supportive care designed to enhance patient knowledge, promote understanding, and facilitate positive adjustment while minimizing distress.^{46,47} Patient education strategies often include a variety of planned educational activities, and may implement a combination of teaching, counselling, and behavior modification techniques to improve patients' knowledge and encourage positive health behaviors.⁴⁸ Common methods used to deliver patient education include traditional strategies, such as lectures, discussions, instructional videos, and

written materials.⁴⁸ However, educational support practices may vary according to patients' individual needs and preferences.⁴⁸

Patient education in cancer populations has been linked to numerous benefits including decreased treatment-related symptoms (e.g. anxiety, depression, nausea, and vomiting), as well as improved clinical outcomes, such as decreased length of hospital stay, better adherence to treatment, and reduced need for post-operative pain medications.⁴⁹⁻⁵¹ Educational interventions have also shown to be effective in decreasing cancer-related fatigue, as well as improving HRQOL and physical function in cancer survivors.⁵² Evidence has further indicated that cancer survivors who are provided with high-quality information pertaining to their diagnosis may be less likely to experience psychosocial difficulties such as depression and anxiety when compared to uninformed or misguided patients.^{53,54}

1.6.1. Evidence for Patient Education Materials

In 2009, Bennett et al. conducted a systematic review and meta-analysis investigating the efficacy of educational interventions for managing pain in cancer survivors.⁴⁹ Educational interventions were defined as information, behavioural instruction, or advice regarding the management of cancer -related pain by means of verbal and/or written communications, as well as audio, video, or computer aided modalities delivered by health care providers. Studies implementing psycho-behavioural methods such as mediation or relaxation techniques were excluded in order minimize confounding variables. Inclusion criteria was limited to experimental control trials investigating the effects of patient-centered education interventions on pain-related outcomes in adult survivors of various cancer types. Twenty-one studies from six countries were included, 19 of which were randomized control trials. The majority of interventions incorporated in person coaching combined with printed patient informational materials. Nine studies reported

a single exposure to intervention, seven reported a single exposure with phone call follow-up, and five reported greater than 3 exposures to the intervention.⁴⁹

Of the 16 studies that reported pain intensity outcomes, 12 utilized the same Brief Pain Inventory questionnaire and were therefore considered suitable for meta-analysis.⁴⁹ Statistical analysis found that average pain intensity decreased by one point (weighted mean difference -1.1, 95% confidence interval (CI) -1.8 to -0.41).⁴⁹ Maximum pain intensity also decreased by approximately one point (-.78, 95% CI -1.21 to -0.35). Similar results were reported for minimal pain intensity (-0.98, 95% CI -1.68 to -0.28). Current pain intensity showed smaller, yet still significant reductions (-0.65, 95% CI -1.21 to -0.09). Due to the high degree of heterogeneity among the studies included in this review, authors were unable to examine the effects of pain on interference with daily living activities. However, as pain intensity has shown to be highly correlated with functional status in cancer survivors, these results indicate that educational interventions may offer increased benefits to individuals coping with cancer-related functional impairments.^{49,55,56}

Cancer survivors of varying types have recognized the value of quality cancer-specific informational resources, and frequently emphasized the need for educational support.⁶²⁻⁶⁴ The majority of cancer survivors prefer to be provided with comprehensive information relating to their diagnosis and treatment, and numerous survivors have cited knowledge-seeking behaviors as an effective method of managing and attenuating the stress commonly experienced throughout the cancer trajectory.⁵⁷⁻⁶⁰

One patient education approach of relevance is providing the information required to undertake self-management, defined as the tasks that individuals undertake to manage the symptoms, physical and psychosocial consequences, and lifestyle changes inherent to living with

a long-term health condition.⁵² Specific to cancer survivors, the National Health Service has defined self-management as “the awareness and active participation by the person with cancer in their recovery, recuperation, and rehabilitation, to minimize the consequences of treatment, promote survival, and health and well-being”⁶¹ (p. 2). Research has indicated that cancer survivors who engage in regular self-management behaviors may be better equipped to make informed decisions and cope with the long-term consequences of their diagnosis.^{53,54} As a result, education interventions targeting self-management skills have been acknowledged as an important component of oncology rehabilitation care.^{46,47}

Unfortunately, cancer survivors frequently express dissatisfaction with the information provided to them, particularly in regard to the management of treatment-related side effects and the post-treatment recovery process.⁶²⁻⁶⁵ In addition to the desire for more appropriate and comprehensive education, cancer survivors often report having received conflicting advice or recommendations from various health care professionals.⁷¹⁻⁷² Contradictory information has been recognized by many cancer survivors as a source of anxiety, confusion and frustration, often leading to increased feelings of stress, uncertainty, fear, and decreased perceived ability to cope.⁶⁸⁻⁶⁹ The association between knowledge acquisition and psychological factors such as stress and depression may have important implications on HRQOL and disease free survival, as distress and depression have been linked to poorer cancer outcomes.⁶⁵⁻⁶⁷ As a result, access to comprehensive educational resources have been recognized as a key strategy in the management of common treatment-related side effects, such as pain, fatigue, depression, and anxiety, making it an important component of comprehensive oncology rehabilitation.⁴⁷

1.6.2. Role of Health Literacy

The WHO has defined health literacy as “The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use info in ways which promote and maintain good health”⁶⁸ (page. 2). Health literacy has therefore been recognized as a critical factor in patients’ ability to process and understand basic health information.⁷⁶ Research has consistently shown correlations between health literacy, disease knowledge, and utilization of preventative services, on outcomes such as risk of hospitalization, control of chronic disease, overall health status, and mortality.⁶⁸

Research investigating the impact of health literacy on cancer outcomes has found low health literacy to be associated with poorer HRQOL, lower treatment adherence, and adverse health behaviours, such as unfavorable exercise, smoking, and dietary habits.^{69,70} Despite the pressing implications of health literacy, primary care providers are often unable to accurately recognize and respond to patient health literacy limitations.⁷¹ Current data suggests that up to 60% of the Canadian population lack the necessary knowledge/health literacy skills to make appropriate health care decisions, demonstrating the need for improved communication and education strategies.⁷² Therefore, it is important to consider health literacy levels when designing patient education materials for cancer survivors.

1.6.3. Role of Patient Education Materials

Written instructional resources have been identified as an effective method of conveying health information to patients with limited health literacy, and have been recognized as an important component of health communication.⁷³ Numerous randomized control trials utilizing printed educational materials to promote health behaviors such as exercise and self-management of physical side effects among cancer survivors have reported promising results, indicating that

written educational materials may be an effective strategy for increasing physical activity and improving HRQOL.^{73,74} Furthermore, studies investigating survivors' perspectives on patient education strategies have found written educational resources to be the preferred method of delivery for many cancer survivors, as even the most comprehensive oral communications have the potential to be misinterpreted or forgotten by patients.^{74,75} As a result, there is justification for emphasizing the importance of written patient education materials for cancer survivors.

1.7. Delivery of Oncology Rehabilitation

1.7.1. Gaps in Oncology Rehabilitation

Despite compelling evidence demonstrating the efficacy of physical rehabilitation and education in managing and attenuating multiple unfavorable side effects associated with cancer treatment, many cancer survivors are unable to access appropriate rehabilitation care.^{16,37} Barriers to adequate physical rehabilitation are multifarious and may include personal and/or systemic limitations.^{76,77} Common personal barriers are financial and transportation restrictions, and inability to adhere to rehabilitation programming due to treatment side effects.^{76,77} Examples of systemic barriers include lack of funding, lack of resources such as equipment and space, and lack of education among other health care professionals regarding the benefits of oncology rehabilitation.⁷⁷ Consequently, there have been ongoing calls from professional organizations of rehabilitation professionals (i.e., physical therapists and physiatrists) and other stakeholders for greater integration of physical rehabilitation as part of supportive care for cancer survivors.^{15,78,79}

There is awareness of the need to address current gaps in the delivery of oncology rehabilitation care, and to develop recommendations for key stakeholders responsible for the planning of national initiatives in oncology rehabilitation.¹⁵ In 2016, the Clinical Centre Rehabilitation Medicine Department at the National Institutes of Health (NIH) in the United

States convened an interdisciplinary group of cancer rehabilitation experts, including researchers and clinicians from across the United States, to review the available research literature and develop consensus recommendations. The summary findings were: 1) although oncology rehabilitation programs are effective at improving numerous health outcomes, other health care professionals generally lack knowledge regarding evidence-based practices and comprehensive oncology rehabilitation care; 2) clinical integration of rehabilitation programming for cancer survivors is limited, indicating the need for conscious efforts to enhance the knowledge and inclusion of oncology rehabilitation practices in clinical health care settings; and 3) a multi-pronged approach requiring the participation of a variety of health care professionals, patients, and advocacy groups, as well as research funding organizations, policy makers and financial regulatory bodies in prioritizing the delivery of oncology rehabilitation was needed.¹⁵

1.7.2. Oncology Rehabilitation in Canada

In Canada, a similar consensus regarding the current state of oncology rehabilitation programming and recommendations on future direction was developed through a three-day workshop held in 2013 and published by McEwen et al.⁷⁹ Workshop attendees included individuals from a diverse range of backgrounds, including researchers, physical therapists, occupational therapists, oncologists, nurses, as well as cancer survivors. Group brainstorming activities, individual reflection, and large group discussions were used to help participants reach a consensus identifying key areas for future research and education relating to oncology rehabilitation, as well as priorities regarding the delivery of rehabilitation care for cancer survivors. The resulting recommendations were the need to: 1) prioritize including assessment of side effects of cancer treatment at different times during the cancer trajectory and the subsequent development of personalized rehabilitation programs; 2) increase education and awareness

among health care providers and patients on the need for and effectiveness of oncology rehabilitation; and 3) develop and implement an effective referral process to ensure cancer survivors are receiving the appropriate rehabilitation care at the appropriate time in the delivery of oncology care.⁷⁹

Data regarding the availability and content of oncology rehabilitation services in Canada has shown to be especially limited. To date, there has been a single published study investigating the provision of rehabilitation programs for cancer survivors in Canada.³⁷ In 2011, Canestraro et al. investigated the practice patterns and provision of oncology rehabilitation programs across Canada in a cross-sectional study. The primary study aims of this study were to: 1) explore the extent of oncology rehabilitation provision in Canada; 2) characterize the nature of the programs including types of patients and providers; and 3) describe the perceived barriers to and facilitators of oncology rehabilitation service provision for cancer survivors, as identified by health care providers. The inclusion requirements included hospitals, community centres, and private clinics which offered cancer treatment and/or were identified as offering rehabilitation services to individuals who had undergone treatment for cancer. Health care sites providing oncology care were identified via online search, as well as through contact with major cancer centres across Canada, including The Canadian Cancer Society, and Cancer Care Ontario. Facilities restricted to pediatric, acute care, or home rehabilitation care were excluded.³⁷

A total of 179 health care centres (165 hospitals, and 14 private centres) were identified as oncology care providers. Telephone contact was made with each identified site up to four times to: 1) determine site eligibility criteria; and 2) identify the individual most familiar with the provision of physical rehabilitation for cancer survivors at the respective health site. Individuals who provided consent and contact information were e-mailed a web-based survey consisting of

27 items designed to characterize oncology rehabilitation programs in Canada. Examples of questions asked included: “Does your facility offer an oncology rehabilitation program? “Is there a waiting list for your oncology rehabilitation services or program?”; “Which health care professionals are involved in rehabilitation for oncology patients?”; and “Is the oncology rehabilitation service/program meeting the needs of your patients?”³⁷

A total of 116 health care sites were contacted successfully, of which 115 consented to participate. Of the 115 recruited sites, 62 (53.4%) completed the survey. Twenty sites identified having an oncology-specific rehabilitation program, the majority of which were located in Ontario (10) and Quebec (5). Forty-one respondents reported no formal oncology rehabilitation programming, and one respondent was unsure. Of the 20 oncology-specific programs identified, 15 were located in a metropolis (population > 500 000), and 5 in an urban centre (population > 50 000). The size of cancer-specific programs ranged from 7 to 100 participants per week, with duration ranging from 8-30 weeks, and session frequency ranging from 1-5 times per week. However, of the nine sites that responded to this question, four did not report frequency or duration averages, instead stating that each varied depending on patients’ needs. The largest cancer-specific program, which treated approximately 100 participants per week, reported the greatest variation in program duration, stating that some patients may complete a single visit, while others may attend for over a year. The majority of sites offering site offering cancer-specific programming indicated that the rehabilitation services provided were individualized based on patients’ needs, with only one site reporting that all patients participated in a similar, standardized rehabilitation program. Further, of the 20 sites which identified as having a rehabilitation program specific to cancer survivors, 10 provided information regarding the program’s specific components, eight of which reported providing aerobic exercise, psychosocial

therapy, and educational services. Other components of oncology-specific programs included strength training, lymphedema management, and speech and language therapy. Moreover, of the 20 sites offering oncology-specific rehabilitation, 17 provided information regarding the involvement of various health care professionals in their site's oncology rehabilitation program. Physical therapists were the most involved health care professionals, with 17 (100%) of respondents identifying a physical therapist as being the individual most involved in the delivery of oncology physical rehabilitation services. However, all 17 programs reported the involvement of numerous health care professionals, including dietitians, registered nurses, and occupational therapists. The majority of programs reported treating cancer survivors of various types, however, breast cancer survivors were the most frequent oncology population, with two of the 20 identified programs being unique to breast cancer, and 6 programs reporting treating primarily breast cancer survivors. None of the identified rehabilitation programs were exclusive to survivors of other cancer types. The majority of sites did not consider current programs to be sufficient, with 80% indicating that the services being provided were not adequately meeting the rehabilitation needs of their oncology population. Respondents were located in all provinces, with the exception of Nova Scotia and British Columbia.³⁷

1.8. Issues Specific to Breast Cancer

Breast cancer is the most common female malignancy in Canada, affecting nearly 25, 700 women nationwide each year.² Fortunately, advancements in breast cancer therapies, including surgical procedures, such as sentinel and axillary node biopsy, endocrine therapy, along with anthracycline and taxane based chemotherapies have positively affected breast cancer survival rates. Currently, the five-year relative survival rate for women diagnosed with breast cancer in Canada is 88%.² However, despite significant progress in survival outcomes, breast cancer

survivors continue to experience a variety of challenges both during and following their course of treatment.⁸⁰⁻⁸³ Common sequelae associated with breast cancer treatment include physical impairments such as pain syndromes, neuropathy, cardiotoxicity, compromised bone health, and lymphedema.⁸⁰⁻⁸³ Numerous breast cancer related impairments may persist long term, and can have significant effects on survivors' functional abilities, HRQOL, and survival outcomes.^{82,83} However, research has shown many of these side effects to be highly responsive to physical rehabilitation and exercise interventions.^{84 85}

1.8.1. Arm Morbidity and Breast Cancer

A common treatment-related side effect unique to breast cancer survivors is impaired upper body function, frequently referred to as arm morbidity.⁸⁵ Arm morbidity after breast cancer is typically characterized by the presence of sensory, motor or muscular skeletal issues in the shoulder, arm, and/or breast of the affected side.⁸⁵ Common concerns associated with arm morbidity include pain, edema, weakness, tightness, poor ROM, nerve palsies, altered movement patterns or muscle recruitment, numbness, or axillary web syndrome.⁸⁵ These issues can in turn lead to upper body functional impairments, and often have profoundly negative effects on survivor's productivity and QOL.^{86,87}

One issue of particular note is the development of secondary lymphedema.^{87,88} Trauma to the lymphatic nodes caused by lymphatic node dissection surgery and axillary targeted radiation treatment can result in compromised lymphatic function, which may lead to inefficient lymphatic fluid clearance, and eventually result in excessive localized swelling known as secondary lymphedema.^{87,89} Lymphedema may in turn lead to additional pain, tightness, weakness, numbness, stiffness, paresthesia and decreased ROM in the affected region.^{87,88} Ultimately, lymphedema may decrease healing capacity of the affected tissues, putting women at higher risk

of infection due to breaks in the skin of the arm, as well as depression, anxiety, and body image concerns.^{86,87}

1.8.2. Prevalence of Upper Body Morbidity

Research has consistently shown that upper body morbidity among breast cancer survivors is common, with observational and cross-sectional studies suggesting that up to 50% of breast cancer survivors experience some form of arm morbidity either during treatment, and/or following treatment completion.^{88,90} In 2008, MacLean et al. conducted a cross-sectional study examining the prevalence of upper body impairments among 347 Canadian breast cancer survivors within 12 months post-surgery.⁹¹ Clinical assessments were conducted to obtain objective measures of upper body ROM and arm volume, while self-report questionnaires were used to investigate HRQOL outcomes, such as pain, psychosocial well-being, and ability to perform daily living activities. Results indicated that approximately 50%, 39%, and 12% of participants experienced ROM restrictions, physical pain, and lymphedema, respectively. An additional key finding reported by MacLean et al. was that pain and ROM restrictions were strongly correlated with functional status and productivity.⁹¹

These findings are comparable to another cross-sectional study conducted by Miedema et al in 2008 in Canada, which reported that at 12-months post-surgery, 55% of breast cancer survivors demonstrated upper body ROM restrictions, 34.5% reported experiencing pain, 48.5% reported difficulties performing activities that involved force and/or impact, 44% reported limitations with daily living activities requiring full upper body ROM, and 29% reported challenges participating in leisure activities.⁹²

1.8.3. Physical Rehabilitation for Arm Morbidity

Although breast cancer related arm morbidity can significantly impact survivors' HRQOL and functional well-being, research has shown the majority of these complications to be responsive to appropriate rehabilitation interventions, such as physical therapy, massage, exercise, compression garments, and education. In 2015, De Groef et al. completed a systematic review on the effectiveness of various postoperative physical therapy on pain and upper body ROM in breast cancer survivors.⁹³ In the 18 randomized controlled trials that met the eligibility criteria, 15 studies tested a single modality such as passive mobilizations, manual stretching, massage, myofascial therapy, and therapeutic exercise (e.g, active stretching and ROM). Three of the reviewed studies investigated the effects of a multimodal physical therapy program combining active exercise with passive mobilization and/or stretching techniques. De Geof et al. concluded that multifactorial physical therapy programming including both active and passive exercises may offer further benefit in treating postoperative pain and impaired ROM in breast cancer survivors when compared to single modality approaches.⁹³

1.8.4. Prospective Surveillance and Arm Morbidity

Prospective surveillance has been proposed by a consensus statement by a panel of experts and stakeholders convened by the ACS as an ideal approach to identify arm morbidity early, provide target physical therapy treatment and ultimately attenuate the unfavorable outcomes associated with arm morbidity in breast cancer survivors. Prospective surveillance in breast cancer rehabilitation is defined as a patient-centered, proactive approach involving regular functional assessments and ongoing support before, during, and after treatment regardless of current impairment status.⁹⁴⁻⁹⁶ Prospective surveillance models are based on the notion that survivors be consistently monitored for physical function, regardless of impairment status, in an

effort to detect and mitigate progressive conditions, while ensuring prompt delivery of appropriate rehabilitation interventions.⁹⁵⁻⁹⁷

The benefits of a prospective surveillance model of care for women with breast cancer are well documented.^{94,95} Evidence has shown prospective physical rehabilitation interventions to be effective in increasing upper body function and strength, as well as decreasing the prevalence and severity of pain and upper body impairments and preventing progression of lymphedema.⁹⁴

Many breast cancer survivors have also expressed support for a prospective approach to physical rehabilitation and education. In a review of the literature of patient perspectives on rehabilitation as part of the ACS consensus panel, Binkley et al. found that many breast cancer survivors are unaware of the side effects commonly associated with their diagnosis and the long-term impact they can have on QOL.⁹⁶ Numerous qualitative interview studies have also shown that breast cancer survivors frequently report feeling unprepared to cope with the side effects they experience as a result of their treatment, and have consistently conveyed the desire for earlier, more frequent access to physical rehabilitation and higher quality education regarding arm care and upper body concerns.⁹⁶

1.8.5. Clinical Practice Guidelines for Breast Cancer

Given the documented benefits of physical therapy for breast cancer survivors, it is not surprising that numerous agencies have published clinical practice guidelines (CPGs) pertaining to breast cancer rehabilitation. Of particular relevance to rehabilitation care for breast cancer survivors in BC, the CPGs developed by The BC Cancer Agency (BCCA) have advocated for a prospective surveillance approach to breast cancer rehabilitation, and recommend that all breast cancer survivors receive ongoing monitoring and assessment of upper

extremity functioning, beginning pre-operatively and continuing regularly throughout the first year following treatment.³⁴ Additional CPGs developed by the BCCA advise that physical therapy should commence the first day following surgery, with stretching exercises beginning one week post-surgery and continuing until full ROM is achieved. The BCCA further recommends that breast cancer survivors be instructed regarding proper hand and arm care, including scar tissue massage and proper hygiene, in order to minimize the risk of future complications, such as cellulitis and lymphedema.³⁴

1.8.6. Gaps in Delivery of Rehabilitation for Arm Morbidity

Unfortunately, across the research literature breast cancer survivors generally report receiving little to no physical therapy, as well as receiving conflicting advice and recommendations from health care workers in regards to arm care and self-management.⁹⁸ Consequently, there is an urgent need to provide breast cancer survivors with appropriate rehabilitation care and patient education in order to ensure they are receiving the support necessary to properly recognize and manage treatment-related side effects, as well as adjust to life beyond cancer treatment.

In 2010, Lee et al. conducted a cross-sectional study in Australia investigating perspectives regarding arm care and advice following surgery in 175 breast cancer survivors who had undergone surgery for breast cancer 6-15 months prior.⁶⁴ Approximately 72% of participants reported having received advice from a health care professional relating to upper body care and activity. Specific to that advice, this was most commonly received from physicians, nurses, physical therapists, and occupational therapists.

Despite evidence indicating the effectiveness of therapeutic exercise and rehabilitation in managing and alleviating upper body concerns in breast cancer survivors, 70% of respondents

reported avoidance of upper body exercise, primarily due to recommendations provided by their treating health care professionals.⁶⁴ Of note, breast cancer survivors who had received advice from a health care professional regarding upper body issues were five times more likely to avoid upper body activity and exercise when compared to participants who had not received any upper body related advice or recommendations. Respondents also consistently asserted dissatisfaction with the information and or advice they had received concerning upper body morbidities, care and use, including conflicting or inadequate advice relating to upper body exercise, deficient educational resources, failure to acknowledge upper body concerns by health care professionals, absence of follow-up physical therapy, and a lack of knowledge among health professionals regarding upper body care, exercise, and function. Together, the findings reported by Lee et al. emphasize the importance of patient-centered education, and illustrate the need for improved education aimed at health care practitioners responsible for delivering breast cancer rehabilitation.⁶⁴

Despite the existence of a national health care system, oncology rehabilitation and follow-up care in Canada remains inconsistent, often varying by geographic location.³⁷ Furthermore, arm morbidities have shown to be frequently under-diagnosed, under recognized, and under treated by Canadian health care professionals.⁹⁰ In 2008, an investigation conducted by Thomas-MacLean et al reported that although arm morbidity was highly prevalent following breast cancer treatment, the majority of survivors had not received adequate physical rehabilitation care or educational guidance. In addition, >60% of participants who had experienced arm morbidity reported having not discussed options for physical rehabilitation therapy with a health care professional, indicating an urgent need for improved access to breast cancer rehabilitation and education services.⁹⁰

1.9. Conclusion

Cancer survivors endure complex physical side effects as a result of their diagnosis and ensuing treatment. Many of these side effects can persist long term, and significantly impact patients' functional capacity. Physical therapy has consistently been deemed effective in ameliorating many of the physical impairments associated with cancer treatment, and is widely recognized as a necessary component of supportive cancer care. However, despite urgent need, oncology rehabilitation services in Canada have shown to be highly limited and do not meet the needs of cancer survivors. Given the array of benefits associated with oncology rehabilitation, combined with lack of data on the current availability of oncology rehabilitation and practices specific to BC, a comprehensive evaluation of the oncology rehabilitation services currently available within BC is warranted.

1.10. Research Objectives

The primary aim of this study is to assemble a comprehensive description of the physical therapy services publically available to cancer survivors in BC. Results from this study will provide a descriptive summary of the current physical rehabilitation care provided to cancer survivors across the province (objective 1), assemble additional information specifically on publicly-funded physical rehabilitation services that are specific to breast cancer survivors (objective 2), and evaluate the content of patient education materials provided specifically to breast cancer survivors in BC (objective 3). It is anticipated that this study will serve to identify current gaps in the delivery of oncology rehabilitation care in BC, and provide valuable insight regarding potentials for new developments aimed at increasing the access to oncology rehabilitation services for cancer survivors in BC.

Chapter 2: Methods

2.1. Study Purpose

The primary aim of this study was to assemble a comprehensive description of the content and availability of publicly-funded physical therapy services available to cancer survivors in BC. The secondary aim was to assemble additional information on the content of publicly-funded physical rehabilitation services specific to breast cancer survivors. The tertiary aim was to evaluate the content of patient education materials provided to breast cancer survivors through the public health care system.

2.2. Study Design

The study used a quantitative study design, using a survey tool-developed specifically for the study. As the investigation was exploratory in nature, there was no established study hypothesis. The study was conducted at the University of British Columbia-Point Grey campus, with Dr. Kristin Campbell acting as the primary investigator. Ethics approval was obtained from The University of British Columbia's Clinical Research Ethics Board prior to the commencement of data collection.

2.3. Study Recruitment

A standardized survey was utilized to collect information regarding the current rehabilitation programs and services available to cancer survivors within BC's public practice health care system. All publicly-funded health care sites across BC were contacted and questioned regarding the nature of the physical therapy services provided to cancer survivors at their location. To ensure survey responses accurately reflected each health care site, the

professionals most familiar with the delivery and content of physical therapy services at their location (i.e., physical therapy practice/site leaders) were requested to complete the survey.

2.3.1. Health-Care Sites

Publicly-funded BC health care sites were identified through a combination of The Public Practice Advisory Committee of the Physiotherapy Association of BC (PABC) and the BC government's official public health care website (gov.bc.ca). A comprehensive list of public BC health care sites offering physical therapy services was first attained from PABC. This list was then cross-referenced with all public hospitals listed on the official BC public health care website to ensure all primary health care facilities were identified in the final contact list. A primary health care facility was defined as a public health care site that is not exclusive to a specific health condition (e.g., spinal cord injury, or fall prevention). All health care sites were then organized by Provincial Health Authority, namely, Fraser Health, Interior Health, Northern Health, Vancouver Coastal Health, and Vancouver Island Health Authority. Within each health care authority, health care sites were organized according to: 1) Type (i.e., hospital or out-patient); 2) location (i.e., population); 3) number of beds; 4) capacity to perform surgery (i.e., equipped with operating rooms and surgeons on staff); and 5) provision of cancer surgery for tracking and analysis purposes.

2.3.2. Participants

Contact information for each health care site was attained from a comprehensive distribution list of publicly practicing physical therapy leaders and their respective locations compiled by PABC, which we were granted permission to use through personal communication with Vancouver Coastal Health Physical Therapy Public Practice Leader, N. Cho. Contact was

first initiated by phone, using phone numbers listed on the PABC contact list. In cases where phone numbers were incorrect or not in service, contact was made with the general health care centre information line (i.e., switchboard, operator, reception) to establish whether or not physical therapy services were available at the respective site. For sites offering physical therapy services, phone contact was made through either the extension or telephone number designated to the physical therapy department in order to identify the individual most appropriate for participation. If necessary, further contact information for the correct individual was attained from department staff. In cases where initial phone contact was unsuccessful, up to three follow up phone calls were made. Follow-up phone calls were made at weekly intervals, spaced 5 working days apart. If phone contact was unsuccessful after three attempts, e-mail contact was attempted up to three times. If e-mail contact information was missing or incorrect, no further contact was made and the site would be designated as non-responsive. If contact remained unsuccessful after three follow-up e-mails, no further contact was made and the site would be designated as non-responsive. If e-mail contact information was missing or incorrect, the facility was re-contacted to request another potential contact person.

Upon successful phone contact, individual leaders were familiarized with the study purpose and requested to complete an approximately 15-20 minute survey that could be executed either online or by phone. When suitable, surveys were completed over the phone during the initial phone conversation. If requested, appointments to conduct the survey over the phone at a later date and/or time were scheduled. In cases where participants' preferred to complete the questionnaire online, e-mail contact information was confirmed and survey links were distributed accordingly.

2.4. Survey

The survey was developed specifically for this study, with guidance from various team members regarding content and usability. Factors demonstrated to increase response rates of online surveys, such as survey brevity, clarity, and simplicity were incorporated to the survey design to ensure maximal response rate.⁹⁹ The survey was designed to be non-burdensome and easy to execute, taking approximately 15 minutes to complete. As a first step, the proposed survey was reviewed in detail by the study team and the Knowledge Broker of the Department of Physical Therapy at the University of British Columbia (A. Hoens). This feedback was used to update the survey. For step two, this version of the survey was reviewed by three professional practice leaders for occupational therapy within the Fraser Health Authority to pilot test the survey for usability and provided feedback regarding content and clarity. The goal with this step was to have individuals with similar positions to those who would be approached for the study to test the instrument, while not sampling our group of interest. Feedback received from pilot testing was then incorporated into the final version to ensure maximal comprehensibility and ease of use.

The survey consisted of 40 items, the majority of which were in multiple choice or checklist format, and inquired about the nature of the physical therapy services being provided to cancer survivors at each health care site (Appendix A). In order to gather additional data specific to breast cancer, the survey was divided into two sections. The first section of the survey pertained to cancer survivors in general, and inquired about fundamental features of the oncology rehabilitation services offered at each site. To gather information on rehabilitation services unique to breast cancer, the survey included a secondary section inquiring specifically about the physical rehabilitation programming and services offered to breast cancer survivors. The survey consisted of questions designed to provide information on the setting (in-patient or out-patient),

provision of physical rehabilitation (i.e., physical therapy) services for cancer survivors, including amount (i.e., number of sessions), type of services (i.e., manual therapy versus rehabilitation exercises) and formats of delivery (i.e., one-on-one, remote, or group based). Sites that indicated “yes” to providing physical rehabilitation services for cancer survivors were asked to specify if these services were oncology-specific (i.e., part of a rehabilitation program exclusive to cancer survivors) or non-specific (i.e., part of the site’s general physical therapy services).

Further topics of interest included: 1) primary reasons for referral (i.e., mobility/locomotive impairments, pain, swelling, difficulties with daily living activity/reduced physical function, reduced muscular strength/general weakness, range of motion deficiencies; 2) whether current services were adequately meeting patient needs; and 3) potential barriers to meeting patient needs. The survey also inquired about demographic characteristics of the site (i.e., location, population served). The secondary section included questions similar to those in the primary section, however, but inquired specifically about the physical rehabilitation services that addressed the distinct needs of breast cancer survivors, such as programs or educational resources targeted at reducing arm morbidity. Finally, the survey included narrative, two open-ended questions (one at the end of each section) to allow respondents to comment on any relevant information not addressed by specific survey questions (e.g., staffing concerns, other nearby rehabilitation services).

The surveys were administered using an online web-based system (Fluid Survey). Individuals completed directly via email or if the survey was completed by phone, the researcher (S. Sayyari) completed the survey on-line while the respondent provided the responses over the phone. Each individual was given a unique ID number to manage tracking of respondents and

follow-up e-mails to request completion of the survey. All completed surveys were hosted on Canadian servers and immediately downloaded onto a password-protected computer located within The Department of Physical Therapy, at The University of British Columbia, Vancouver Campus. All participants were entered to win one of two \$300 vouchers, valid to utilize toward any PABC-hosted continuing professional development course or vodcast as a participation incentive.

2.5. Assessment of Education Materials

In order to identify and evaluate the educational materials being offered to breast cancer survivors within BC, the secondary section of the survey inquired about the provision of written patient educational materials specific to breast cancer rehabilitation. Participants were first asked whether their site distributed written educational materials to breast cancer survivors that aimed to provide guidance on post-operative physical rehabilitation and therapeutic exercise. Sites that indicated “yes” to this question were requested to specify the source, title, and version number of the educational materials being distributed. Electronic versions of each educational material were subsequently retrieved by internet search for analysis purposes. Following collection, materials were assessed using methods outline by Friedman et al. for: 1) readability; 2) suitability; and 3) content accuracy.¹⁰⁰

2.5.1. Readability

Readability refers to the reading difficulty of a material, and can have significant impact on patients’ ability to comprehend written educational resources.^{101,102} It has been recommended that reading level for patient education materials should be at the 6th grade level, however, research has shown that many patient education materials do not meet this

recommendation.^{101,102} Consequently, reading level has been identified as an important consideration when evaluating the quality and efficacy of patient resources.^{101,102} Readability of patient education materials was assessed using the F-K formula, which has been repeatedly validated and has been identified as the most commonly used tool in the evaluation of the readability of patient education materials.¹⁰³ Microsoft Word was used to apply the F-K formula to the full text of each written educational resource in order to determine a Flesch reading ease score for each (0-100; higher score indicating better readability). Each material's Flesch reading ease scores were then converted into a score out of 10 for final scoring purposes.

2.5.2. Suitability

Suitability of a written educational resource can be defined as how well the material can be understood and accepted by the intended reader.^{74,100} The suitability of a resource refers to factors beyond reading level, such as communication style, sentence structure, and visual representation, and has been identified as an important indicator of the quality of patient education materials.^{74,100}

The Suitability Assessment of Material (SAM) instrument was used to evaluate the suitability of the identified resources. The SAM instrument is a validated 27-item form that has been repeatedly recommended for use in the assessment of patient educational resources.¹⁰⁰ To obtain a comprehensive overview of education materials' quality, the SAM instrument rates health educational sources by the following categories: 1) content; 2) literacy demand; 3) graphics; 4) layout; 5) learning stimulation and motivation; and 6) cultural appropriateness. The SAM asks raters to rank various aspects of the above categories as either: Superior (2 points); Adequate (1 point); or Not Suitable (0 points). The SAM scoring system allows users to generate scores for each category, as well as overall, by summing the total number of points per

category.¹⁰⁰

Each education material was assessed by two independent reviewers. Any discrepancies in SAM scoring were discussed by both reviewers until a consensus was reached. Agreed upon scores were subsequently calculated for each category and summed to generate a total overall score.

2.5.3. Content Accuracy

Content accuracy was assessed to ensure the breast cancer education materials being distributed are providing survivors with up to date evidence-based recommendations. Material content was assessed based on the following four themes: 1) recommendations pertaining to lymphedema prevention; 2) recommendations regarding lymphedema management; 3) recommendations for post-operative rehabilitation; 4) recommendations for physical activity. Scientific literature was searched in order to review the current CPG's pertaining to each theme and identify primary recommendations for each. Potential options for the primary recommendations for each was reviewed and discussed with two additional members of the study team to get consensus on which source would be used for each theme. Upon review, key recommendations for each theme were compiled to allow for content scoring. The content in the patient education materials collected was subsequently compared to the CPG's specific to each theme, and granted one point per recommendation, for a total possible score of 20 points.

2.6. Outcome Variables

2.6.1. Demographic Outcomes

Descriptive outcome variables pertaining to site demographics and delivery of care were used to develop a comprehensive overview of the oncology rehabilitation services available

throughout BC. Descriptive site variables included: 1) population of location served (i.e., metropolis (population >500, 000) urban center (population 50, 000 - 500, 000), town (population <50, 000)); 2) type (i.e., hospital or health care center); 3) health authority (i.e., Fraser, Interior, Northern, Providence, Island, Vancouver Coastal Health); 4) provision of surgery at the site (Y/N), as if yes, provision of surgery for cancer (Y/N); 5) number of beds.

Descriptive statistics were further used to provide detail regarding the rehabilitation services offered to cancer survivors at each site. Descriptive variables pertaining to oncology rehabilitation consisted of: 1) provision of physical rehabilitation of cancer patients (Y/N); 2) presence of an oncology-specific physical rehabilitation program (Y/N); 3) practice areas (i.e., musculoskeletal, neurological, palliative, outpatient, in patient, respiratory, homecare, amputations, surgery rehabilitation, general medical conditions, such as cardiovascular disease, diabetes; 4) primary reasons for referral (i.e., mobility/locomotive impairments, pain, swelling, difficulties with daily living activity/reduced physical function, reduced muscular strength/general weakness, ROM deficiencies); 5) services meeting patient needs (Y/N); 6) barriers to availability of care (i.e., funding, lack of resources, lack of administrative support, lack of space, lack of health care professionals).

2.6.2. Breast Cancer Outcomes

Breast cancer-specific outcomes included: 1) provision of written education materials (Y/N); 2) provision of specific lymphedema therapy/education (Y/N); 3) timing of care (i.e., pre-operative, immediate post-operative, out-patient); 4) provision of pro-active post-operative follow-up to identify potential issues (Y/N); 5) content of provided rehabilitation (i.e., consultation with a physical therapist, assessment of upper extremities, provision of

rehabilitation exercises, manual therapy, education regarding lymphedema or upper extremity exercises).

2.6.3. Education Material Outcomes

Outcome variables for education materials included: 1) reading level score (0-10); 2) SAM score (0-42); and 3) content score (0-20). Individual scores were then converted into a percentage to rate each outcome variable according to the SAM guidelines: <39%= inadequate, 40-69% = adequate, or 70-100%=superior. All data analysis was conducted at The University of British Columbia using Microsoft excel 2016 software.

Chapter 3: Results

3.1 Response Rate

In the process to develop the final contact list, four potential sites were excluded as either a long-term care centre or not a primary health care facility. A total of 98 public health care sites in six health care authorities (Fraser, Interior, Vancouver Coastal, Providence, Northern, and Island) were identified for the final contact list and contacted for participation. Settings included hospitals (n=75) and community health care centers (n=23). Of the 98 sites identified, 93 (95%) were contacted successfully. Of these, 92 (99%) completed the survey, for a total response rate of 94% (Figure 1). Of the 75 hospitals identified, 70 (93%) completed the survey. Responses were received from 22 (96%) of the 23 identified community health care sites. Of the 68 surgically-equipped sites, responses were received from 65 (96%), and of the 30 non-surgically-equipped sites, responses were received from 27 (90%) (Table 1).

3.2 Demographics

Respondents were located throughout BC, specifically in the: Interior Health Authority, n=31 (34%); Fraser Health Authority, n=23 (25%); Island Health Authority, n=13 (14%); Northern Health Authority, n =13 (14%), Vancouver Coastal Health, n=8 (9%); and Providence Health Authority, n=4 (4%) (Table 1). Fifty-four (59%) of sites were located in rural communities (population <50,000), while 27 (29%) of sites were located in urban centers (population 50,000-500,000), and 11 (12%) of sites were located in a metropolitan centre (population > 500,000) (Figure 2). Of the 65 surgically-equipped sites, 42 (65%) performed cancer related surgeries, 22 (34%) did not conduct cancer surgeries, and one (2%) was unsure (Table 1). Twenty-seven (29%) of sites were non-surgical health care centers.

Twenty (22%) of sites did not provide any physical rehabilitation services for cancer

survivors, and one (1%) was unsure. Of the 71 (77%) sites that provided rehabilitation services to cancer survivors, 69 (97%) did not offer a formal oncology rehabilitation program and two (3%) reported having a formal oncology rehabilitation program (Surrey Memorial and Mount St. Joseph's Hospitals). Both oncology-specific physical rehabilitation programs were located in the Lower Mainland of BC, and exclusive to breast cancer survivors (Table 2).

3.3. Practice Areas

Of the 71 sites that provided oncology rehabilitation services, the most common practice areas were: out-patient musculoskeletal care, n=63 (89%); neurological care, n=52 (73%); amputation care, n= 48 (68%); out-patient homecare n=32 (45%); palliative care n=34 (48%); and care for general medical conditions, n=34 (48%) (Table 2).

This pattern differed by type of facility, namely between hospitals versus community health care sites. For the 51 hospitals that provided oncology rehabilitation services, 42 (82%) provided out-patient musculoskeletal care, 33 (65%) provided care for general medical conditions, 32 (63%) provided palliative care, and 32 (63%) provided neurological care. (Table 2).

Of the 22 community health care sites that offered oncology rehabilitation services, 21 (95%) provided out-patient musculoskeletal care, 21 (95%) provided out-patient homecare, 20 (91%) provided out-patient neurological care, 20 (91%) provided out-patient care for amputations, 2 (9%) provided out-patient palliative care, and 1 (5%) provided out-patient care for general medical conditions (Table 2).

3.4. Reasons for Primary Referral

Of the sites that offered oncology rehabilitation, the most common reasons for referral were: mobility or locomotive impairments, n=65 (92%); reduced physical function/ability to perform activities of daily living, n=59 (83%); muscular strength or general weakness, n=37 (52%), ROM deficits, n=29 (41%), swelling or lymphedema, n=17 (24%), and pain, n=10 (14%) (Table 2).

3.5. Meeting Patient Needs

Forty-four percent of respondents considered the current oncology rehabilitation services offered at their site to be sufficient, 21% of respondents reported the services being offered at their site were not meeting the needs of their patients, and 35% were unsure. However, when asked specifically about the unmet needs of breast cancer survivors, 55% of sites providing breast cancer rehabilitation considered current services to be adequate, 17% did not consider current services to be meeting the needs of their breast cancer population, while 28% were unsure (Table 3). Sites perceived ability to meet patients' needs also varied by location. Seventy percent of sites within Fraser Health Authority, 29% within the Interior Health Authority, 75% of sites within Providence Health Authority, and 25% of sites within Vancouver Coastal Health Authority considered current services to be adequately meeting the rehabilitation needs of their oncology population. Eight percent of sites located within the Island and Northern Health Authorities considered current services to be sufficient. Forty-nine percent of sites located in urban or metropolitan settings considered current services to be adequately meeting the needs of their patients, compared to only 19% of sites located in towns.

Thirty-eight percent of sites within The Northern Health Authority did not consider current services to be adequate, in comparison to 9% located within Fraser Health, 13% within

Interior Health, 15% within Island Health and 13% within Vancouver Coastal Health. None of the sites located within Providence Health Authority considered current services to be insufficient (Figure 4).

The most common reasons cited for current services not meeting the needs of patients were lack of funding (83%), lack of health care professionals with experience in oncology rehabilitation (73%), lack of resources (70%), lack of administrative support (50%), and lack of space (45%) (Table 2).

3.6. Barriers to Availability of Care

The most frequently reported reason for lack of offering a formal oncology rehabilitation program was that patients were being offered non-cancer-specific rehabilitation services, which was reported by 78% of the sites offering non-specific programming. Other barriers to offering a formal oncology rehabilitation program included lack of funding (61%), lack of health care professionals with expertise in oncology rehabilitation (58%), small oncology patient population (55%), lack of resources (48%), lack of administrative support (25%), and lack of space (23%) (Table 2).

3.7. Breast Cancer Specific Outcomes

3.7.1. Demographics

A total of 64 sites (70%) reported providing rehabilitation services for breast cancer survivors, 26 (28%) did not offer any breast cancer rehabilitation services, and two (2%) were unsure. Thirty-three (36%) of responding sites performed surgical services for breast cancer, 58 (63%) of sites did not perform breast cancer surgery, and one (1%) was unsure (Table 3).

3.7.2. Practice Areas

Of the 33 sites that performed surgery for breast cancer, 88% provided breast cancer rehabilitation services. Forty-eight provided breast cancer rehabilitation services to individuals undergoing surgery as standard practice. Sixty-four percent of sites provided immediate post-operative, in-patient physical rehabilitation services for breast cancer survivors, 45% offered out-patient breast cancer rehabilitation services, 24% conducted follow-up rehabilitation care (i.e., after initial discharge) as part of the breast cancer surgery care pathway, and 9% offered pre-operative rehabilitation services for breast cancer (Table 3).

Of the 58 of sites that did not conduct surgery for breast cancer, 66% provided rehabilitation for breast cancer. Sixty-six percent offered out-patient rehabilitation services for breast cancer survivors. Twenty-four percent provided pre-operative rehabilitation services, and 29% offered follow-up rehabilitation sessions for breast cancer survivors (Table 3).

3.7.3. Description of Services

Of the 64 sites that offered some form of breast cancer rehabilitation, 70% provided survivors with rehabilitation exercises, 69% conducted upper extremity assessments, 64% provided education regarding lymphedema, 63% provided consultation with a physical therapist, 61% provided education regarding upper extremity exercises, and 30% provided manual therapy. Of the sites offering breast cancer rehabilitation, 55% considered current services to be sufficiently meeting patient needs; 17% described current breast oncology services as inadequate, and 28% were unsure (Table 3). None of the responding sites reported offering formal distance based rehabilitation services (i.e., telephone or web based sessions).

3.8. Access to Care

In narrative responses to the two open-ended questions regarding access to care, eleven surgical sites that did not provide post-operative rehabilitation following breast cancer surgery primarily indicated that this was due to the majority of patients' receiving surgery for breast cancer being discharged shortly after their operation has been completed so there was insufficient time at the time of surgery. Notably, ten of these sites reported having previously treated breast cancer survivors as in-patients immediately post-surgery, however, no longer have the capacity to do so as a result of financial cutbacks. Six sites also specified that their ability to provide breast cancer survivors with in-patient rehabilitation care depended significantly on the treating physical therapist(s) schedule and availability, further demonstrating the impact of financial resources on quality of care.

Further narrative responses provided insight into the staffing situations at various health care facilities. Eleven (12%) of sites, all of which were located in towns, reported having only one physical therapist on staff. Four (7%) of sites indicated that there was no physical therapist or other rehabilitation professional working on staff. Of these, three (75%) were not aware of any practicing physical therapist within at least 100 km. All four of these sites were located in rural communities within The Northern Health Authority. Seventeen (31%) of sites located in towns did not provide any oncology rehabilitation services, in comparison to 23 (100%) and 24 (89%) of sites located in metropolitan and urban settings, respectively.

3.9. Education Materials

3.9.1. Provision of Education Materials

Forty-one (45%) of all sites provided written education materials for breast cancer survivors, 37 (40%) of sites did not distribute any patient education materials, and 14 (15%)

were unsure. Of the 41 sites that did provide breast cancer education materials, 35 (85%) utilized the same “Exercises After Breast Cancer Surgery” booklet produced by The Canadian Cancer Society.¹ Three sites (7%) utilized the “Breast Cancer Surgery” patient education material developed by Vancouver Coastal Health,² two sites (5%) utilized a resource titled “Physiotherapy After Your Breast Cancer Surgery” developed by Providence Health,³ and one site (2%) distributed the “Functional Rehab After Breast Cancer Surgery” resource developed by Mount Sinai Hospital⁴ (Table 4) (Appendix B).

3.9.2. Content Assessment

The Canadian Cancer Society’s “Exercises After Breast Cancer Surgery” material was the highest rated patient education material, which received a readability score of 89% (approx. 6th grade), a SAM score of 93%, and a content score of 75%. The education material developed by Mount Sinai Hospital had the second overall highest scores, with a readability score of 72% (approx. 8th grade), a SAM score of 93%, and a content score of 75%. The breast cancer patient education material distributed by Vancouver Coastal Health received a readability score of 75% (approx. 7th grade), a SAM score of 86%, and a content score of 80%. The educational resource utilized by Providence Health had a readability score of 76% (approx. 7th grade), a SAM score of 71%, and a content score of 60%. All educational materials were found to be of superior quality (>70% in all scoring categories), with the exception of that used by Providence Health Care, which was deemed to be adequate (<70% in at least one scoring category) (Tables 5 & 6).

All education materials failed to include at least four of the 20 CPG’s identified by the study team, these however, varied significantly between materials. For example, elevating the upper extremities following surgery was recommended by all resources with the exception of those developed by The Canadian Cancer Society. In contrast, The Canadian Cancer Society’s

“Exercises After Breast Cancer Surgery” booklet was the only education material to recommend using compression garments and avoiding restrictive jewelry and/or clothing following surgery for breast cancer. The education material developed by Vancouver Coastal Health was the only resource to recommend that breast cancer survivors engage 150 minutes of moderate intensity aerobic activity per week. Nineteen out of the 20 identified guidelines were included in at least one of the materials, with avoidance of prolonged sitting being the only recommendation not addressed by any of the respective resources.

3.10. Tables for Chapter 3

Table 1. Site Demographics	no. respondents	% of category	% of total
Sites identified n=98			
<u>Health Authority</u>			
Interior (n=33)	31	94%	34%
Fraser (n=23)	23	100%	25%
Northern (n=16)	13	81%	14%
Island (n=14)	13	93%	14%
Vancouver Coastal (n=8)	8	100%	9%
Providence (n=4)	4	100%	4%
<u>Location</u>			
Metropolis (n=11)	11	100%	12%
Urban (n=27)	27	100%	29%
Town (n=60)	54	90%	59%
<u>Setting</u>			
Community health care (n=23)	22	96%	24%
Hospital (n=75)	70	93%	76%
Beds			
< 50 (n=32)	28	88%	30%
50-100 (n=13)	12	92%	13%
100-250 (n=14)	14	100%	15%
250-500 (n=13)	13	100%	14%
500 ≤ (n=3)	3	100%	3%
<u>Surgically-equipped</u>			
Yes (n=68)	65	96%	71%
Surgery for cancer			
Yes	42	65%	46%
No	22	34%	24%
Don't know/unsure	1	2%	1%
No	27	90%	29%

Legend: Metropolis-population > 500, 000; Urban centre-population >50, 000; Town-population < 50, 000; Hospital-Medical institution that provides emergency and diagnostic health care services in which patients are required to be admitted for at least one night; Surgically-equipped- Operating room and surgeon on staff

Table 2. Description of Rehabilitation Services	no. respondents	% of category	% of total
Setting			
Hospital (n=70)			
Provision of cancer rehabilitation			
Yes	51	73%	55%
Non-cancer-specific	49	70%	53%
Cancer-specific	2	3%	2%
No	18	26%	20%
Don't know/unsure	1	1%	1%
Community health care (n=22)			
Provision of cancer rehabilitation			
Yes	20	91%	22%
Non-cancer-specific	20	91%	22%
Cancer-specific	0	0%	0%
No	2	9%	2%
Don't know/unsure	0	0%	0%
Practice areas			
Hospital (n=51)			
Out-patient musculoskeletal	42	82%	46%
General medicine	33	65%	36%
Palliative	32	63%	35%
Neurological	32	63%	35%
In-patient musculoskeletal	28	55%	30%
Amputations	28	55%	30%
General surgery	27	53%	29%
In patient respiratory	23	45%	25%
Homecare	11	22%	12%
Community health care (n=22)			
Out patient musculoskeletal	21	95%	23%
Homecare	21	95%	23%
Neurological	20	91%	22%
Amputations	20	91%	22%
Palliative	2	9%	2%
General medicine	1	5%	1%

Legend: ADL- Activities of daily living

Table 3. Breast Cancer Specific Outcomes

	no. respondents	% of category	% of total
Provision of breast cancer rehabilitation			
Yes	64		70%
Content			
Provision of rehabilitation exercises	45	70%	49%
Assessment of upper extremity	44	69%	48%
Education for lymphedema	41	64%	45%
Consultation with a physical therapist	40	63%	43%
Education for upper extremity	39	61%	42%
exercises			
Provision of manual therapy	19	30%	21%
Other (i.e., prosthetic training)	2	3%	2%
Meeting needs			
Yes	35	55%	38%
No	11	17%	12%
Don't know/unsure	18	28%	20%
No	26		28%
Don't know/unsure	2		2%
Provision of breast cancer surgery			
Yes	33		36%
Provision of breast cancer rehabilitation			
Yes	29	88%	32%
Rehabilitation as standard care	16	48%	17%
Immediate in-patient rehabilitation	21	64%	23%
Out-patient rehabilitation	15	45%	16%
Pre-operative rehabilitation	3	9%	3%
Follow-up rehabilitation	8	24%	9%
No	3	9%	3%
Don't know/unsure	1	3%	1%
No	58		63%
Provision of breast cancer rehabilitation			
Yes	38	66%	41%
Out-patient rehabilitation	38	66%	41%
Pre-operative rehabilitation	14	24%	15%

Table 3. (continued)			
	no. respondents	% of category	% of total
No	24	41%	26%
Don't know/unsure	1	2%	1%
<u>Barriers to meeting patient needs</u>			
Lack of funding	27	93%	29%
Lack of specialized health care professionals	25	86%	27%
Lack of resources	24	83%	26%
Lack of space	9	31%	10%
Lack of administrative support	5	17%	5%

Table 4. Education Materials

	no. respondents	% of category	% of total responses
<u>Provision of written materials</u>			
Yes	41		45%
Material 1 (CCS)	35	85%	38%
Material 2 (VCH)	3	7%	3%
Material 3 (Prov)	2	5%	2%
Material 4 (MS)	1	2%	1%
No	37		40%
Unsure	14		15%

Legend: CCS – Canadian Cancer Society; VCH-Vancouver Coastal Health; Prov- Providence Health Authority; MS- Mount Sinai Hospital

Table 5. Assessment of Education Materials	no. respondents	% total
<u>Material 1 (CCS)</u>		
Readability score (10)	8.9	89%
Content score (20)	15	75%
SAM score (42)	39	93%
Literacy demand (10)	10	100%
Graphics (10)	10	100%
Learning stimulation (6)	4	67%
Content (6)	5	83%
Layout (6)	6	100%
Cultural sensitivity (4)	4	100%
<u>Material 2 (VCH)</u>		
Readability score (10)	7.5	75%
Content score (20)	16	80%
SAM score (42)	36	86%
Literacy demand (10)	9	90%
Graphics (10)	7	70%
Learning stimulation (6)	5	83%
Content (6)	5	83%
Layout (6)	6	100%
Cultural sensitivity (4)	4	100%
<u>Material 3 (Prov)</u>		
Readability score (10)	7.6	76%
Content score (20)	12	60%
SAM score (42)	30	71%
Literacy demand (10)	10	100%
Graphics (10)	5	50%
Learning stimulation (6)	2	33%
Content (6)	4	67%
Layout (6)	5	83%
Cultural sensitivity (4)	4	100%
<u>Material 4 (MS)</u>		
Readability score (10)	7.2	72%
Content score (20)	15	75%
SAM score (42)	39	93%
Literacy demand (10)	10	100%
Graphics (10)	9	90%
Learning stimulation (6)	5	83%
Content (6)	5	83%
Layout (6)	6	100%
Cultural sensitivity	4	100%

Table 6. Education Material Content					
Source	Evidence-based recommendations	CCS	VCH	PROV	MS
National Breast and Ovarian Cancer Centre (2008) Review of Research Evidence on Secondary Lymphedema: Incidence, Prevention, Risk Factors	1. Regular exercise and muscle contractions	√	√	√	√
	2. Avoid restrictive jewelry and clothing	√			
	3. Avoid sitting in one position for 30 minutes				
	4. Elevation of limb		√	√	√
	5. Avoid strenuous exertion activity/over lifting	√	√		√
(Armer et al. 2013): Best Practice Guidelines Assessment, Risk Reductions, Management, and Surveillance for Post-Breast Cancer Lymphedema	1. Use of compression garments	√			
	2. Gentle strengthening exercises	√	√	√	√
	3. Maintain healthy weight		√		
	4. Proper skincare and avoidance of infection	√	√		√
	5. Ongoing self-management	√	√	√	√
(Harris et al. 2012): Clinical Practice Guidelines for breast cancer rehabilitation	1. Post-operative physical therapy and gentle ROM exercises beginning the first day following surgery	√	√	√	√
	2. Active stretching exercises beginning one week following surgery or as soon as drain is removed, continuing until ROM is achieved	√	√	√	√
	3. Progressive resistance exercises, working up to 1-2 lbs	√	√		√
	4. Gentle shoulder flexion and abduction rehabilitation exercises	√	√	√	√
	5. Self-scar tissue massage			√	√
(Schmitz et al. 2000) American College of Sports Medicine Roundtable on exercise guidelines for cancer	1. 150 minutes/week of moderate intensity aerobic activity		√		
	2. Avoid inactivity	√	√	√	√
	3. Stretch major muscle groups and tendon daily	√	√	√	√
	4. Return to activity as soon as possible following surgery	√	√	√	√
	5. 6-10 rehabilitation exercises, 1-4 sets, 8-10 reps	√	√	√	√
	Total (20)	15	16	12	15

3.11. Figures for Chapter 3:

Figure 1. Flow Chart of Respondents

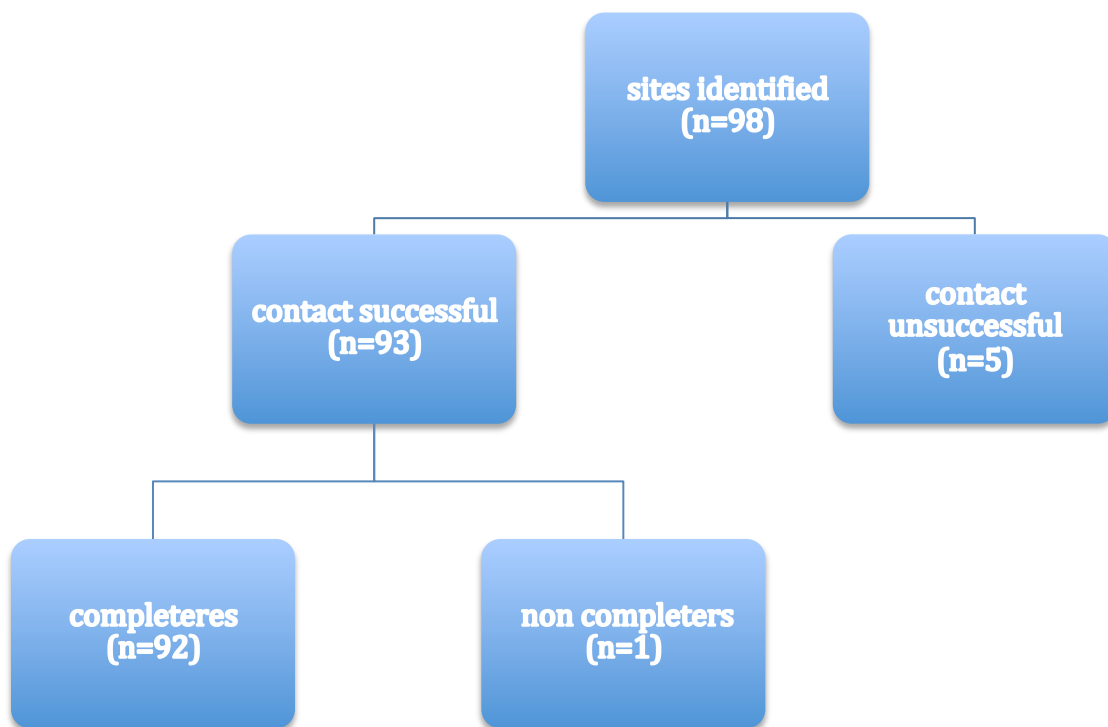


Figure 2. Map of Sites

- ★ Oncology-specific rehabilitation, surgery
- ★ Non-specific rehabilitation, surgery
- ★ Non-specific rehabilitation, no surgery

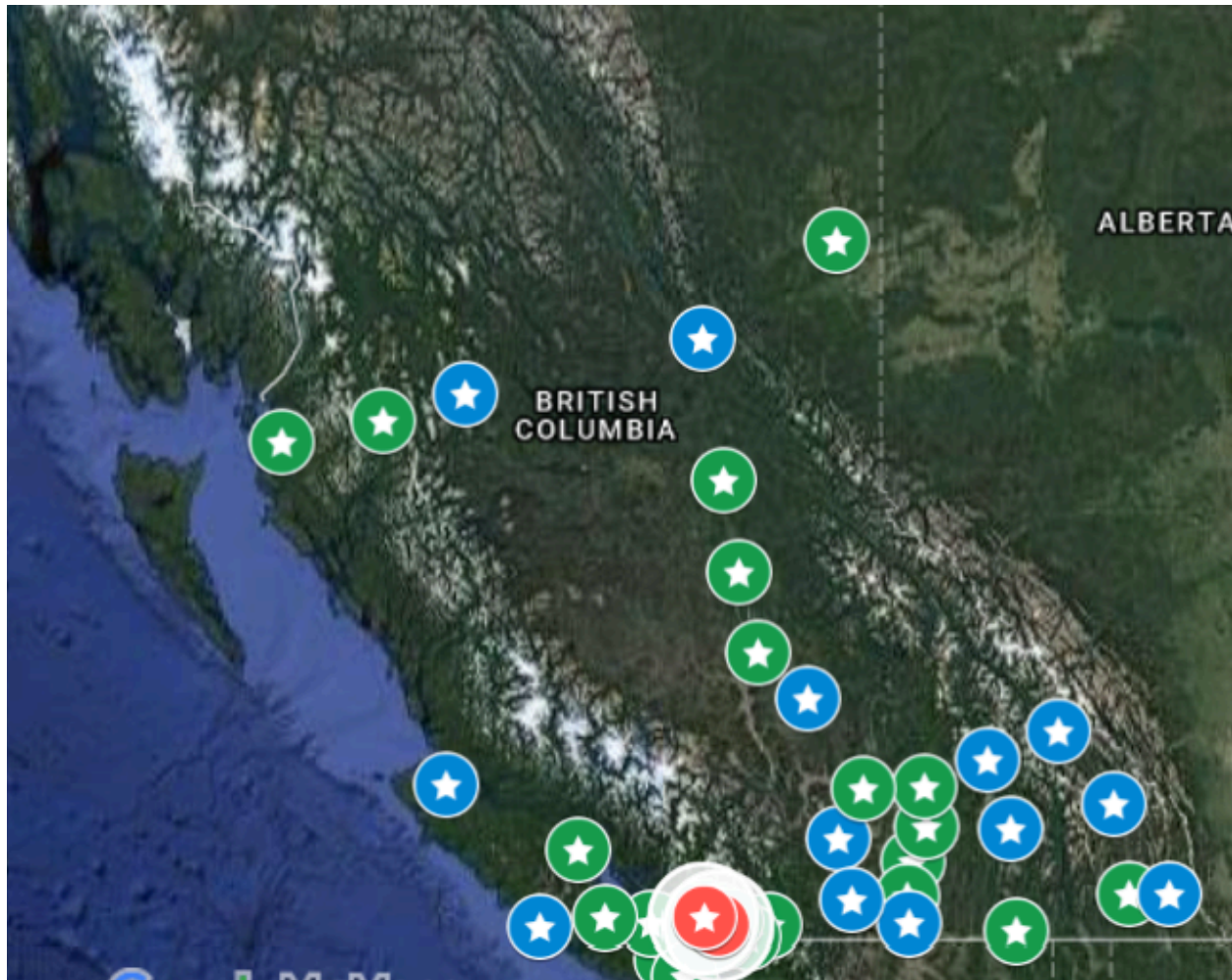


Figure 3. Percent of Sites Offering Oncology Rehabilitation

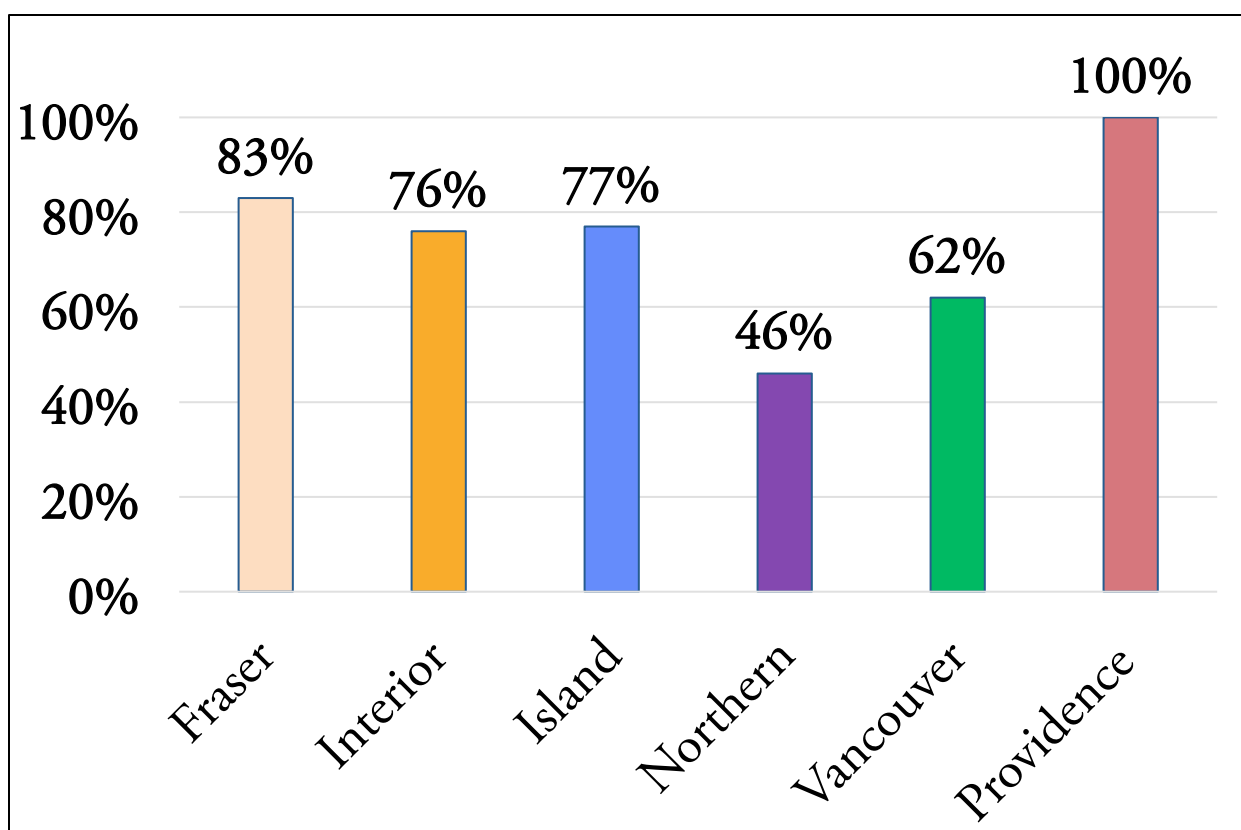
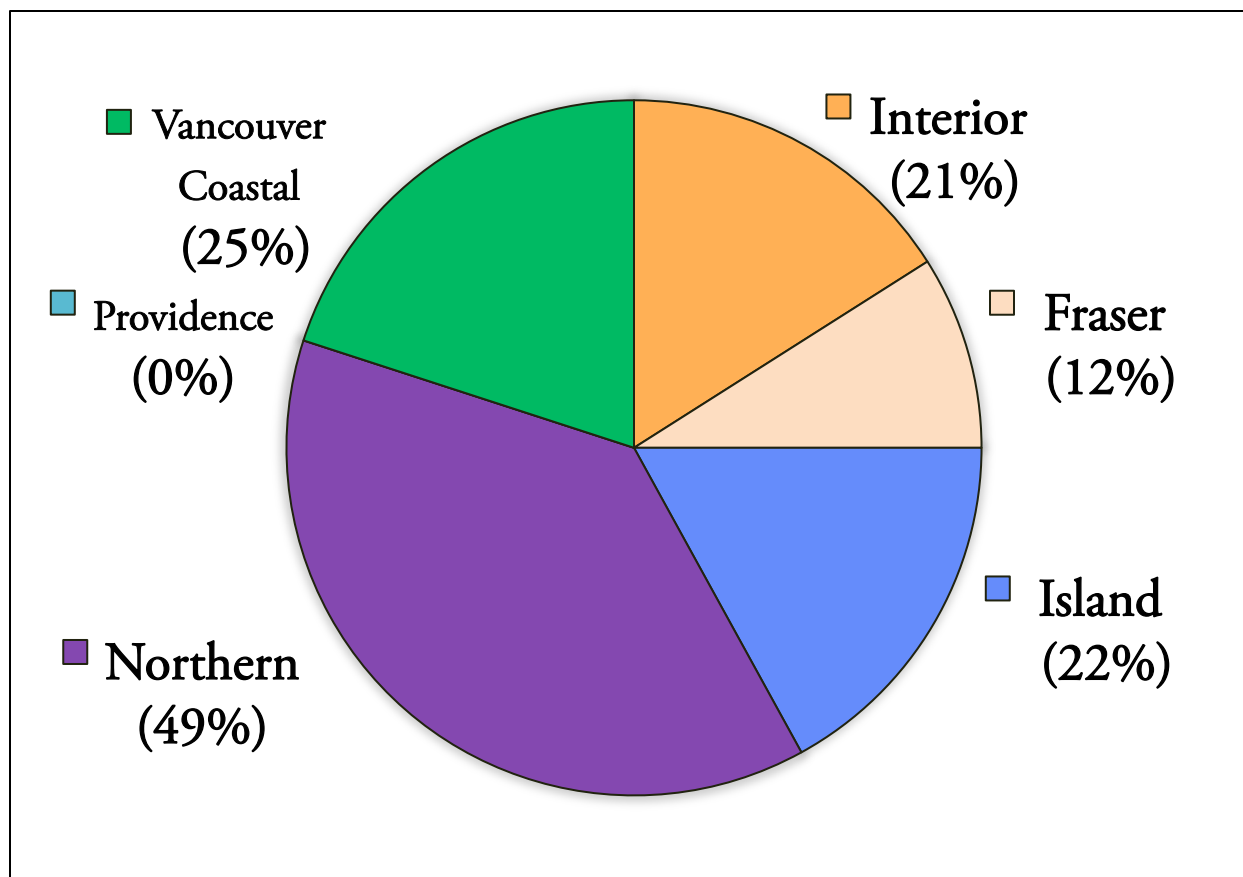


Figure 4. Percent of Sites Not Meeting Patients Needs



Chapter 4: Discussion

4.1. Introduction

To date, this has been the first investigation to identify and describe the rehabilitation services available for cancer survivors through public health care sites in BC. With a response rate of 94%, only two public health care sites in BC identified as having a formal oncology rehabilitation program, both of which were exclusive to breast cancer survivors and located in the Lower Mainland of BC. This indicates that publicly funded formal oncology rehabilitation programs in BC are not only scarce, but also highly limited in terms of scope and accessibility.

4.2. Oncology Rehabilitation Services

Despite this lack of formal programs, 77% of surveyed health care sites in BC do report providing rehabilitation services for cancer survivors. These sites indicated that the services provided were based on patients' individual health care needs rather than diagnosis. For example, cancer survivors requiring rehabilitation for a cancer-related amputation would be referred to the services provided for those with amputations from any cause for their rehabilitation care, while patients coping with an orthopedic ROM limitations due to a cancer surgery would receive rehabilitation treatment within the site's out-patient orthopedic unit. This finding is consistent with those of Canestraro et al., which similarly found that cancer survivors are frequently referred to general rehabilitation care as a result of limited oncology-specific rehabilitation services or formal programs.³⁷ Given that the population of cancer survivors in BC is expected to increase rapidly, it will be important to establish whether the non-specific rehabilitation services currently being provided to cancer survivors will be sufficient to meet the demands of a growing patient population.

Although research has yet to establish whether participation in oncology-specific

rehabilitation programs is preferable to non-specific rehabilitation, evidence has supported the efficacy of oncology-specific rehabilitation programs in improving numerous patient outcomes.⁴³ Furthermore, it has been suggested that health care professionals who are familiar with the complications associated with cancer treatment are better able to recognize the unique needs of cancer survivors, making them better-equipped to develop and administer appropriate treatment plans.⁴³ Therefore, it has been repeatedly suggested that rehabilitation for cancer survivors should be administered by health care professionals who are educated and experienced in the delivery of oncology rehabilitation.^{35,43,104} This approach to oncology rehabilitation has been supported by The CARE, which suggest that rehabilitation services provided by therapists trained specifically in oncology result in improved patient outcomes, as the therapists have greater knowledge regarding the side effects of cancer treatments, and are more skilled in addressing the psychosocial and physical needs of this unique patient population.^{35,43}

Research has also consistently indicated that patient rehabilitation programs should be tailored specifically to each patient's individual needs, as the physical consequences of cancer treatment may vary significantly from patient to patient.⁴³ Furthermore, it has been suggested that outcome measures used to track patient progress should also be individualized.¹⁰⁴ Gilchrist et al. in a 2009 framework for assessing the efficacy of oncology rehabilitation.¹⁰⁴ The framework recommends that outcome measures be informed by patient's personal and environmental factors, including both objective and patient reported outcomes, as well as diagnostic screening tools that have demonstrated to be effective in assessing cancer outcomes. As a result, Gilchrist et al. advocate that physical rehabilitation specialists should consider individual patients' health concerns when determining which outcome measures to employ during baseline, continuing, and final assessments.¹⁰⁴

While it is unclear whether increasing access to oncology-specific rehabilitation programs will be necessary to improve the functional status of cancer survivors in BC, it is evident that rehabilitation professionals throughout the province should be familiarized with the benefits and delivery of oncology rehabilitation practices.

4.3. Distribution of Oncology Rehabilitation Services

Rehabilitation services for cancer survivors were notably limited in the northern regions of the province. Only 46% of health care sites within the Northern Health Authority provided rehabilitation services for cancer survivors, compared to 50-87% in the rest of the Health Authorities in the province (Figure 3). Furthermore, only 45% of sites within the Northern Health Authority provided rehabilitation to individuals with a breast cancer diagnosis compared to 54-87% in the rest of the Health Authorities in the province. Health care sites located in within the Northern Health Authority were also least likely to report that the available services currently met patients' needs. Thirty-eight percent of respondents from sites located within the Northern Health Authority indicated that current services were not sufficient to meet the rehabilitation needs of their oncology population, in contrast to only 9% of sites within the Fraser Health Authority, and 0% in Providence Health Authority (Figure 3). This differential access to care may be due in part to understaffing in northern regions of the province. In narrative responses, four sites located within the Northern Health Authority reported not having a single physical therapist or other rehabilitation-related health professional on staff, and three of these sites were not aware of any practicing physical therapist(s) within at least 100 km.

The availability of oncology rehabilitation services was also notably impacted not just by geography but also by population. Of the health care sites located in towns, 31% did not provide rehabilitation services for cancer survivors, and 20% reported having only one physical therapist

on staff. In contrast, 100% of metropolitan sites and 89% of sites located in urban settings provided oncology rehabilitation services, all of which were staffed with multiple physical therapists. Of the three urban sites that did not offer oncology rehabilitation services, in narrative responses, all indicated that services were available at an alternative public health care site nearby.

The ability of oncology rehabilitation services to meet the needs of cancer survivors was also notably lower in scarcely populated areas of BC. Forty-nine percent of sites located in a metropolitan or urban setting considered current services to be adequately meeting patients' needs, in contrast to only 19% of sites located in towns. This pronounced difference in the ability of oncology rehabilitation services to meet the needs of cancer survivors by in rural vs. urban and metropolitan regions indicates that cancer survivors living in low population areas of BC may be less likely to receive the rehabilitation care they need. Unsurprisingly, this finding is consistent with those reported by Canestraro et al., who similarly found oncology rehabilitation services to be lacking in scarcely populated areas of Canada.³⁷

These findings are also consistent with those reported by The Canadian Institute for Health Research, who similarly found access to health care services to be disproportionately lower in northern communities of BC, with only 2.8 physical therapists per 10 000 residents, compared to the provincial average of 6.2.¹⁰⁵ Research reported by Roots et al. in 2013 also found a longstanding unavailability of rehabilitation services, particularly for physical therapists and occupational therapists in rural regions of northern BC, ultimately leading to limited access to rehabilitation services for northern residents.¹⁰⁶ Research conducted by Roots et al. in 2013 also found understaffing in rural regions to be pervasive, often leading to rehabilitation specialists in rural regions being required to take on large caseloads, which may lead to

decreased time spent with patients, and potentially reduce quality of care.¹⁰⁶ This is a critical concern for rural residents living with long-term consequences of cancer treatment. Furthermore, research has shown that rural BC residents have higher rates of obesity, diabetes, and cardiovascular disease compared to urban residents.¹⁰⁵ Together, these findings suggest that while rural residents are less likely to have access to rehabilitation, many may also have an even greater need for rehabilitation than other populations.

Providing rural populations with remote health care services via telehealth (i.e., web or phone-based) programming has been recognized as a key component to increasing patient access to health services, and has been shown to be a cost-effective method of providing significant improvements in the quality of care.¹⁰⁷ Research has also shown that telehealth rehabilitation can allow for improved patient knowledge, care coordination, and chronic disease management. Research has further indicated that many patients report better understanding of their condition, and more confidence in their ability to engage in self-management practices as a result of telehealth rehabilitation. Telehealth services may also help to reduce health care costs. In 2011, research conducted by Canada Health Infoway found that Canadians living in rural regions avoided an estimated \$70 million of personal costs and 47 million km of travel due to an increased availability of telehealth services.¹⁰⁷ Unfortunately, none of the health care sites located in the Northern Health Authority or low population regions of BC reported using telehealth programs as a method of delivering rehabilitation care to their oncology population. Considering the array of benefits associated with telehealth services, establishing consistent telehealth rehabilitation programs will be crucial to ensure cancer survivors throughout BC are receiving sufficient rehabilitation care.

Of the 56% sites that did not report meeting the needs of their oncology population (i.e.,

“no” or “unsure”), 83% indicated lack of funding as a primary barrier. Additional operational barriers to meeting the needs of patients included lack of sufficient number of specialized health care professionals to deliver care (73%), lack of resources generally (70%), and lack of space to provide appropriate services (45%). It is presumed that increased funding would remedy these issues to some extent. This highlights another key barrier identified which was lack of administrative support (50%), suggesting that advocacy by physical therapists and patients may be needed to provide a case of a change in service delivery approaches to administrators who make financial decisions about how rehabilitation services are allocated.

4.4. Breast Cancer Rehabilitation Services

Perhaps the most interesting finding from this study is the contrast between the rehabilitation services provided to breast cancer survivors versus those provided to other oncology populations. In addition to the two formal oncology-specific rehabilitation programs in BC being exclusive to breast cancer survivors, a greater number of sites offering non-specific oncology rehabilitation believed current services to be meeting the needs of their breast cancer patient population. Fifty-five percent of sites offering non-specific oncology rehabilitation considered current services to be adequately meeting the needs of their breast cancer patients, compared to 44% of sites, which reported current services to be sufficiently meeting the needs of their entire oncology population.

Despite these findings, it is unlikely that the 3,600 women in BC estimated to receive a breast cancer diagnosis in 2017 would receive an adequate amount of rehabilitation care. The BC Cancer Agency (BCCA) recommends that all women receiving surgery for breast cancer receive a minimum of two functional assessments; first to establish limb size, ROM, and strength, and then to monitor for changes in sensation and/or discomfort in the upper body pre and post-

surgery.³⁴ However, only 64% of sites that performed surgery for breast cancer offered post-operative, in-patient rehabilitation care, and only 9% reported offering pre-operative assessments and patient education regarding appropriate post-operative rehabilitation prior to breast cancer surgery. Using the formal program offered by Surrey Memorial Hospital as an example, each functional assessment requires at least 45 minutes of therapist time. As a result, using even the most conservative estimates would require a minimum of 5400 hours per year, or approximately three full time equivalents specific to delivering breast cancer-specific rehabilitation. Given this, it is highly unlikely that BC's public practice health care system is equipped to meet the rehabilitation needs of breast cancer survivors throughout the province. This is unfortunate, given the documented benefits of pre and post-operative rehabilitation in reducing upper body morbidity associated with surgery and treatment for breast cancer.^{108 95}

4.5. Education Materials

While all of the identified education materials were of high quality and provided appropriate advice regarding rehabilitation exercises following breast cancer surgery, each resource presented with unique deficiencies. Overall, the identified materials scored well on the SAM outcome measure, with the average SAM score being 86%. However, scores varied considerably between the SAM subcategories. Cultural sensitivity, a measure of how well-suited the material's language, logic and learning experience is to the intended audience, was the highest scored subcategory of the SAM, with all materials receiving a score of 100% on this measure, indicating that developers were aware of and accommodating to the diversity among BC's population. Materials generally scored well on the literacy demand (i.e., writing style, vocabulary,) and layout (i.e., organization, structure, formatting) subcategories of the SAM, which both received average scores of >95%. The graphics subcategory (i.e., figures, diagrams)

of the SAM received the most variation, with scores ranging from 50% to 100%, and an average score of 78%. Overall, the learning stimulation (i.e., retention, interactivity) subcategory of the SAM was the most poorly scored, with an average score of 67%. No education materials scored above 83% on the learning stimulation or content subcategories (i.e., summaries, purpose statement, and behavior information of the SAM). These findings suggest that any updates to current education materials or development of new education materials may benefit from incorporating interactive text and/or graphics that encourage patients to think critically and demonstrate their understanding of the material's content, in order to allow for enhanced long-term retention.

All education materials received good readability scores, with an average F-K score of 78%, which translates to approximately 7th grade reading level, only slightly higher than the recommended sixth grade reading level. Content was the most poorly rated of the three scoring categories, with each material failing to provide at least 4 (20%) of the 20 identified evidence-based recommendations. Furthermore, 19 out of the 20 identified evidence-based recommendations were included in at least one of the respective resources, with all materials failing to advise against prolonged sitting. Sedentary behavior, such as prolonged sitting, is now regarded as a risk factor for increased risk of recurrence, which has come to prominence more recently (i.e., after 2014).¹⁰⁹⁻¹¹¹ This may explain why it is not addressed in materials, which were likely developed prior to that. However, there is limited information on the year of publication or authorship on the majority of the patient education materials, which limits the ability to determine when updates may be warranted. These findings indicate that although the majority of CPG's are documented between the four education materials being distributed to breast cancer survivors in BC, none of the respective resources are entirely comprehensive.

In addition to being the most commonly distributed resource, the exercises after breast cancer surgery booklet developed by The Canadian Cancer Society was also the most highly rated education material. However, this material scored significantly lower on the learning stimulation scale of the SAM instrument, and was the only resource that failed to recommend elevating the upper extremities following breast cancer surgery. It may therefore be useful for future developers of breast cancer education materials to draw on multiple resources when informing the content of such materials.

Overall, the patient education materials that were evaluated in this study scored higher on readability, suitability and content in comparison to findings reported by other investigations assessing the quality of patient education materials for cancer survivors. A systematic review of twelve oncology patient materials conducted by Tian et al. in 2014 found readability scores to be significantly lower (more difficult) than the resources identified in this study, with average grade level score being at a ninth-grade level.¹¹² Tian et al. also found mean SAM scores to be significantly lower, with an average SAM score of 51.3 (51%). The education materials being distributed to breast cancer survivors in BC also appear to be superior to other resources in terms of visual representation, as further findings reported by Tian et al. found many materials lacked basic illustrations and graphics. Although differences in content scoring methods make comparison difficult, Tian et al. found that a large majority of patient education materials reviewed lacked key content, such as the association between obesity, smoking and cancer risk. These findings indicate that oncology patient education materials often fail to address key CPG's.¹¹² Other investigations have reported similar deficiencies in patient education materials. In a 2015 systematic review investigating the quality of 300 web-based breast cancer education materials, Alkhalili et al. found average reading level to be significantly higher, with all resources

failing to meet the recommended sixth grade reading level, as well as multiple key evidence based recommendations.¹¹³ These findings are consistent with a multitude of studies which have demonstrated that patient education materials pertaining to other illnesses are often too advanced to be effective, particularly for low literacy populations.⁷⁴ This suggests that the breast cancer education materials being distributed to breast cancer survivors in BC are of high quality in comparison to many other patient resources.

4.6. Strengths and Limitations

A significant strength of this study is the high response rate of 94%. This is in contrast to a response rate of only 53% reported by Canestraro et al., who surveyed health care facilities across Canada who were listed as providing oncology care.³⁷ In addition, no responses were received by Canestraro et al. from any of the sites contacted in BC. This improvement in response rate may be in part due to our higher degree of familiarity with the BC health care system in terms of what facilities to approach and who the professional practice leaders for physical therapy are at each facility, as well as a more concise survey instrument. Another strength of this study is the comprehensiveness of the data collected. Using the approach of completing the surveys by phone resulted in very few surveys with missing or incomplete responses. These results provide a reasonably accurate and comprehensive representation of the types of rehabilitation services available to cancer survivors within the public health care setting BC.

There are several limitations to this study that must be addressed. First, this investigation defined oncology rehabilitation as services delivered by either physical therapists or physiatrists. As a result, rehabilitation services administered by other health care professionals, such as occupational therapists, speech and language pathologists, exercise physiologists, or vocational

rehabilitation specialists were excluded. Second, each survey was completed with the input of only one rehabilitation professional per site, albeit the professional practice lead responsible for physical therapy services for that site. So, in some cases the response may not accurately reflect all the available resources at a site. Further, as this investigation was exclusively focused on publicly funded health care sites within BC, it does not accurately reflect of the number of cancer survivors who seek physical rehabilitation services through private rehabilitation services through the use of extended health benefits. Finally, as this study was exclusive to BC, it is limited in terms of generalizability outside of BC. However, it should be noted that public health care funding is managed provincially, necessitating the investigation of services by province.

4.7. Recommendations for Future Work

Further advocacy is required to emphasize the importance of increasing the availability of rehabilitation services for cancer survivors, particularly in rural and northern regions of BC. Additional research is needed to establish novel methods for delivering rehabilitation services to cancer survivors living in low-population areas of BC, such as telehealth and home rehabilitation programming.

As this study focused solely on the delivery of physical rehabilitation through physical therapy services, further research to evaluate other types of rehabilitation will be required in order to obtain a comprehensive representation of all aspects of oncology rehabilitation services available in BC. Furthermore, considering that a lack of specialized health care professionals was identified by many sites as a significant barrier to meeting the needs of cancer survivors, educating health care professionals regarding the benefits of oncology rehabilitation and in the delivery of oncology rehabilitation will be an important step in improving the rehabilitation care being provided to cancer survivors within BC. This is in line with work by McEwan et al., who

emphasized the importance of increasing education among health care professionals on the benefits of oncology rehabilitation, and including the training of current and future rehabilitation health professionals in the delivery of these services.⁷⁹ Finally, given that many BC cancer survivors are likely to seek rehabilitation through private services, an investigation pertaining to BC's privately-funded oncology rehabilitation services will be necessary in order to gain an accurate representation of the number of BC cancer survivors needing and receiving rehabilitation care.

4.8. Conclusion

This study provides valuable insight regarding the current practice patterns and provision of oncology rehabilitation services in BC. Results of this study demonstrate that oncology-specific rehabilitation programs in BC are limited, with the only two-offered being in the Lower Mainland of BC, and exclusive to breast cancer survivors. Although the majority of sites did offer some form of non-specific rehabilitation to cancer survivors, those residing in northern and rural regions of the province are less likely to receive rehabilitation care. Given the documented benefits of oncology rehabilitation, these findings indicate the need for further development and delivery of services in order to improve the QOL and functional capacity of cancer survivors in BC. Finally, as this study has been the first to identify the physical rehabilitation services available to cancer survivors throughout BC, its findings may help to inform a comprehensive database of sites offering oncology rehabilitation, and aid to facilitate cancer survivors' ability to access such services.

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Appendices

Appendix A

Question 1:

Please select the category that best describes your location.

- Metropolis (>500,000 population)
- Urban centre (>50,000 population)
- Town (<50,000 population)

Question 2:

Does your site provide surgical services for cancer?

- Yes
- No
- Don't know/unsure

Question 3:

Does your site offer physiotherapy services for cancer survivors?

- Yes
- No
- Don't know/unsure

Question 4:

If your site does not offer physiotherapy services for cancer survivors, please indicate potential reasons why.

- Lack of funding
- Lack of space
- Lack of resources (i.e., materials or equipment)
- Lack of rehabilitation professionals with expertise in oncology
- Small oncology patient population
- Lack of administrative support
- Lack of evidence to support oncology rehabilitation
- Other, please specify

Question 5:

Does your site offer a rehabilitation program that is specifically identified to treat cancer survivors?

- Yes
- No
- Don't know/unsure

Question 6:

If your site does not offer a cancer specific rehabilitation program, please indicate potential reasons why. (Check all that apply)

- Lack of funding
- Lack of space
- Lack of resources (i.e., materials or equipment)
- Lack of rehabilitation professionals with expertise in oncology
- Small oncology patient population
- Lack of administrative support
- Lack of evidence to support oncology rehabilitation
- Patients being offered rehabilitation services that are not specific to oncology
- Other, please specify

Question 7:

Are the current physiotherapy services offered to cancer survivors at your site adequately meeting the rehabilitation needs of cancer survivors?

- Yes
- No
- Don't know/unsure

Question 8:

If greater access to rehabilitation services would better meet the needs of cancer survivors, what are the barriers to greater access to oncology physiotherapy services at your site? (Check all that apply)

- Lack of funding
- Lack of space
- Lack of resources (i.e., materials or equipment)
- Lack of rehabilitation professionals with expertise in oncology
- Lack of administrative support
- Lack of evidence to support oncology rehabilitation
- Patients being offered rehabilitation services that are not specific to oncology

- Other, please specify

Question 9:

Please check the statement that best describes your oncology physiotherapy services.

- All patients receive a fairly standardized physiotherapy program
- There is no standardized program and each patient is assessed and treated based on the individual's needs
- Don't know/unsure
- Other, please specify

Question 10:

Please provide an estimate of the total number of full time equivalent (FTE)'s allocated to treating cancer survivors at your site. (37.5 hours/week= 1 FTE) OR the total number of hours per week allocated to treating cancer survivors at your site. (leave blank if unknown)

E.g.: 1 physiotherapist treating cancer survivors 37.5 hours/week = 1 FTE E.g.: 2 physiotherapists treating cancer survivors 10 hours/week each =.53 FTE
Total FTE at your site per week:

OR

Total number of hours at your site per week:

Question 11:

Please provide an estimate of the total FTE of physiotherapists allocated to each of the following oncology populations. (37.5 hours/week=1 FTE)

- Children (0-18 years):
- Adult (19-74 years):
- Geriatric (75 years and older):

Question 12:

In which practice areas do physiotherapists provide services for cancer survivors at your site? (Check all that apply)

- Out-patient musculoskeletal
- In-patient musculoskeletal
- Neurological
- Amputations
- Palliative
- Homecare

- General surgery
- In-patient rehabilitation
- Stem cell transplant
- In-patient acute care
- In-patient respiratory
- General medicine
- Don't know/unsure
- Other, please specify

Question 13:

Please select the three most common reasons for referral to physiotherapy services for cancer survivors at your site. (Check three)

- Range of motion
- Muscular strength
- Pain
- Swelling (e.g., cancer related lymphedema)
- Reduced physical function/functional capacity
- Mobility impairment
- Don't know/unsure
- Other, please specify

Question 14:

Please provide any additional information regarding the physiotherapy services or programs that your organization/site provides for cancer survivors that are not designated within oncology-specific care programs and/or provided by oncology-specific funding. For example, provision of care for cancer survivors within a general acute care medicine unit, rehabilitation unit, or out-patient programs.

PART 2:

The following questions are intended to acquire information **regarding the physiotherapy services offered specifically to breast cancer survivors in British Columbia**. We understand that many breast cancer survivors experience complications or side effects similar to those experienced by persons receiving treatment for other forms of cancer. However, breast cancer survivors often report issues unique to their diagnosis (e.g., lymphedema and limitations in arm mobility).

Please complete the following questions **specifically related to breast cancer survivors only**.

Question 15:

Does your organization/site provide surgical services for breast cancer?

- Yes
- No
- Don't know/unsure

Question 16:

Approximately, how many breast cancer survivors have primary surgery for breast cancer at your site per year?

- 50
- 50-100
- 100-200
- 200-500
- 500+
- Don't know/unsure

Question 17:

Does your site offer physiotherapy services for breast cancer survivors?

- Yes
- No
- Don't know/unsure

Question 18:

If your site does not offer physiotherapy services for breast cancer survivors, please indicate potential reasons why. (Check all that apply)

- Lack of funding
- Lack of space
- Lack of resources (i.e., materials or equipment)
- Lack of rehabilitation professionals with expertise in oncology

- Small oncology patient population
- Lack of administrative support
- Lack of evidence to support breast oncology rehabilitation
- Other, please specify

Question 19:

Do breast cancer survivors receive physiotherapy as part of standard care at your site?

- Yes, all patients
- Yes, some patients
- No
- Don't know/unsure

Question 20:

Are the current physiotherapy services offered to breast cancer survivors at your site adequately meeting the rehabilitation needs of breast cancer survivors?

- Yes
- No
- Don't know/unsure

Question 21:

If greater access to rehabilitation services would better meet the needs of breast cancer survivors, what are the barriers to greater access to breast oncology physiotherapy services at your site? (Check all that apply)

- Lack of funding
- Lack of space
- Lack of resources (i.e., materials or equipment)
- Lack of rehabilitation professionals with expertise in breast oncology
- Lack of administrative support
- Lack of evidence to support breast oncology rehabilitation
- Patients being offered rehabilitation services that are not specific to breast oncology
- Other, please specify

Question 22:

Are breast cancer survivors offered pre-operative physiotherapy sessions at your site?

- Yes
- No
- Don't know/unsure

Question 23:

What do the pre-operative physiotherapy sessions at your site include? (Check all that apply)

- Assessment of upper extremity (i.e., measurement of arm circumference or shoulder range of motion)
- Therapist-led education regarding pre-operative upper extremity exercises
- Therapist-led education regarding lymphedema
- Provision of written materials or information
- Provision of manual therapy
- Provision of rehabilitation exercises (i.e., stretching or range of motion exercises)
- Consultation with a physiotherapist
- Don't know/unsure
- Other, please specify

Question 24:

What is the format of the pre-operative physiotherapy sessions offered at your site? (Check all that apply)

- In person, individual/one on one
- In person, group class
- Individual telephone/skype
- Don't know/unsure
- Other, please specify

Question 25:

Are breast cancer survivors offered immediate post-operative physiotherapy sessions as in-patients at your site?

- Yes
- No
- Don't know/unsure

Question 26:

What do the in patient post-operative physiotherapy sessions at your site include? (Check all that apply)

- Assessment of upper extremity (i.e., measurement of arm circumference or shoulder range of motion)
- Therapist-led education regarding post-operative upper extremity exercises
- Therapist-led education regarding lymphedema
- Provision of written materials or information

- Provision of manual therapy
- Provision of rehabilitation exercises (i.e., stretching or range of motion exercises)
- Consultation with a physiotherapist
- Don't know/unsure
- Other, please specify

Question 27:

What is the format of the in patient post-operative physiotherapy sessions offered at your site? (Check all that apply)

- In person, individual/one on one
- In person, group class
- Individual telephone/skype
- Don't know/unsure
- Other, please specify

Question 28:

Are breast cancer survivors offered post-operative physiotherapy sessions as out-patients at your site?

- Yes
- No
- Don't know/unsure

Question 29:

What do the out-patient post-operative physiotherapy sessions at your site include? (Check all that apply)

- Assessment of upper extremity (i.e., measurement of arm circumference or shoulder range of motion)
- Therapist-led education regarding post-operative upper extremity exercises
- Therapist-led education regarding lymphedema
- Provision of written materials or information
- Provision of manual therapy
- Provision of rehabilitation exercises (i.e., stretching or range of motion exercises)
- Consultation with a physiotherapist
- Don't know/unsure
- Other, please specify

Question 30:

What is the format of the out-patient post-operative physiotherapy sessions offered at your site? (Check all that apply)

- In person, individual/one on one
- In person, group class
- Individual telephone/skype
- Don't know/unsure
- Other, please specify

Question 31:

Is there a maximum number of individual/one on one out-patient physiotherapy sessions that are permitted at your site?

- Yes, please specify maximum number of sessions permitted
- No
- Don't know/unsure

Question 32:

Does your site offer group physiotherapy sessions for breast cancer survivors?

- Yes
- No
- Don't know/unsure
- Other, please specify

Question 33:

Is there a maximum number of group physiotherapy sessions that are permitted at your site?

- Yes, please specify maximum number of sessions permitted
- No
- Don't know/unsure
- Not applicable

Question 34:

Does your site offer telephone or skype physiotherapy sessions for breast cancer survivors?

- Yes
- No
- Don't know/unsure

- Other, please specify

Question 35:

Is there a maximum number of individual telephone/skype physiotherapy sessions that are permitted at your site?

- Yes, please specify maximum number of sessions permitted
- No
- Don't know/unsure
- Not applicable

Question 36:

Does your site include a standard planned follow-up session at specific time point(s) after initial discharge, to check for any persistent deficits or concerns that could be addressed by additional physiotherapy?

- Yes
- No
- Don't know/unsure
- Other, please specify

Question 37:

What is the frequency of the follow-up session(s) after initial discharge from usual physiotherapy treatment within the first year after surgery?

- Varies from patient to patient
- Single session (please specify when this is scheduled to occur in number of **weeks** post-operative)
- Monthly
- Twice per month
- Every three months
- Every six months
- Graduated discharge (gradual decrease in session frequency as appropriate)
- Yearly
- Twice per year
- Don't know/unsure
- Other, please specify

Question 38:

Is there a limit to the number of additional sessions provided if there is an indication of need for additional physiotherapy services identified at a follow-up session?

- Yes, please specify maximum number of sessions permitted
- No
- Don't know/unsure

Question 39:

What is the format of the follow-up physiotherapy sessions offered at your site? (Check all that apply)

- In person, individual/one on one
- In person, group class
- Individual telephone/skype
- Don't know/unsure
- Other, please specify

Question 40:

Does your site provide written (i.e., printed or online) educational materials for breast cancer survivors?

- Yes
- No
- Don't know/unsure
- Other, please specify

Question 41:

Would your site be able to provide us with these educational materials for content analysis purposes?

- Yes
- No
- Don't know/unsure

Question 42:

What is the name of your healthcare site?

Question 43:

What is the title of your position?

Question 44:

Do we have your permission to contact you for more details?

- Yes
- No

If yes,

Name Contact e-mail or phone number:

Thank you for taking the time to complete our survey!

Appendix B

F-K Formula

Developed in 1948 by author and writing consultant Rudolph Flesch, the F-K formula has been identified as one of the oldest and most accurate formulas used for assessing readability¹ The F-K Formula assesses the readability of a text by encompassing average sentence length (ASL) and average number of syllables per word (ASW). Specifically, the formula is $RE = 206.835 - (1.015 \times ASL) - 84.6 \times ASW$. The output produces a score ranging from 0-100, with higher scores indicating better readability.

- Scores between 90.0 and 100.0 are considered easily understandable by an average 5th grader.
- Scores between 70 and 80 are considered easily understood by 6th and 7th graders
- Scores between 60.0 and 70.0 are considered easily understood by 8th and 9th grader
- Scores between 0.0 and 30.0 are considered easily understood by college graduates.

In order to obtain an accurate score, the F-K formula must be applied to the entire text of the document one is scoring. This can be done through online calculators, or in Microsoft word by selecting Word Options > Proofing > Check grammar with spelling, and selecting the “readability statistics” check box. Microsoft word will automatically apply the F-K Formula to the entire text of the document, and generate a reading a Flesch reading score from 0-100.

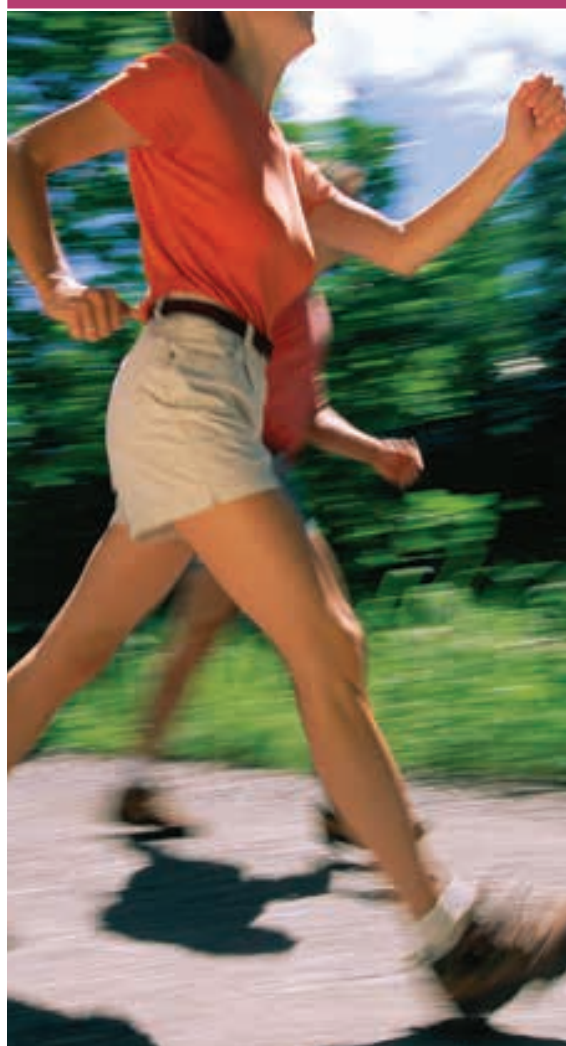
¹ Alkhalli, R. et al.. Readability assessment of internet--based patient education materials related to mammography for breast cancer screening. *Acad Radiol* **22** (2015).



Canadian
Cancer
Society

Société
canadienne
du cancer

Exercises after Breast Surgery



This guide is for anyone who's had surgery for breast cancer. Breast cancer happens mainly in women, but each year a small number of men are also diagnosed. We sometimes refer to *women* in the text, but men who've had surgery for breast cancer may also find this booklet helpful.

The information in this booklet is general and shouldn't replace discussions with your healthcare team.

The Canadian Cancer Society acknowledges the input and guidance from the Canadian Physiotherapy Association.



Canadian
Physiotherapy
Association

Association
canadienne de
physiothérapie

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3	Try to be active
3	Finding a physiotherapist
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18	Second stage of healing – <i>From about 6 weeks after surgery</i>
18	Strengthening
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21	Lymphedema
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Introduction

Exercise is an important part of your treatment and recovery after surgery for breast cancer. It can help you:

- begin your daily activities again (such as bathing and dressing)
- keep movement in your arms and shoulders
- improve muscle strength
- reduce stiffness in your joints
- reduce pain in your neck and back
- improve your overall well-being

Everyone is different and heals at their own pace. Talk to your doctor or another member of your healthcare team before starting the exercises in this booklet, and let them know about your progress.

The timelines suggested are only to guide you. Some exercises can be started right after surgery. More advanced exercises that involve the full range of motion of your shoulder and overhead movements can usually be started once you've had your drain removed. Strengthening and general conditioning exercises can be added to your routine when you've healed more.

📌 If you've had surgery for breast cancer on both sides – for example, a double (bilateral) mastectomy – you can still do some of the exercises in this booklet. The other exercises have been adapted for you. Look for this icon 📌 for notes about how you can change these exercises. Check with your doctor or physiotherapist about what exercises are best for you.

Before getting started

It's important to talk to your doctor or another member of your healthcare team before starting any exercises. Your doctor may suggest exercises or may suggest that you see a physiotherapist or occupational therapist who can measure your range of motion and help design an exercise plan for you.

Remember that everyone recovers at their own pace. Some people may be able to work through the exercises in this booklet quicker than others and with fewer limits.

These general guidelines can help you develop a successful exercise routine:

- Wear comfortable, loose clothing.
- Exercise after a warm shower when your muscles are relaxed and warm.
- Breathe deeply and often as you do each exercise.
- Do the exercises until you feel a gentle stretch, not pain.
- Do not bounce or make any quick, jerky moves while stretching.
- Do the lying-down exercises on the floor or a bed, whichever is best for you.
- Contact your doctor if you have any unusual swelling or pain.

Try to be active

While you need to avoid vigorous exercises and sporting activities in the early weeks after surgery, you can stay active by taking some easy walks throughout the day. Over time, you will be able to walk farther and more often and add other activities. This will give you time to heal, but it will keep you active.

Finding a physiotherapist

To find a physiotherapist in your area who works with women who've had breast cancer surgery, visit the Canadian Physiotherapy Association's website at **physiotherapy.ca**. You can also ask your doctor for a referral or talk to other women who've had breast cancer.

Right after surgery

The first 1 to 7 days

These gentle exercises should be done the first week after surgery, or if you have a drain, while the drain is still in place. It's normal to feel your skin and tissue pull and stretch a bit with these exercises, but be careful not to make any sudden vigorous movements until the incision has healed and the drain has been removed. Repeat these exercises 3 or 4 times a day.

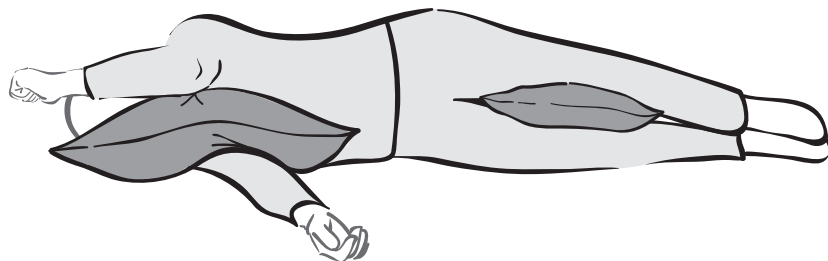
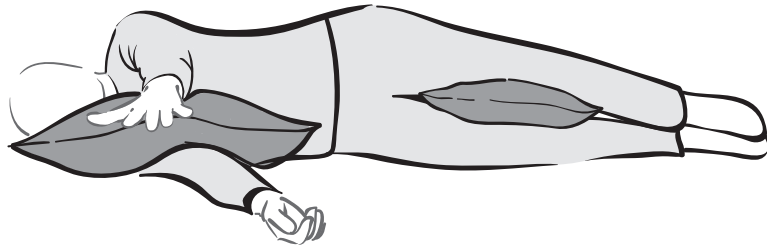
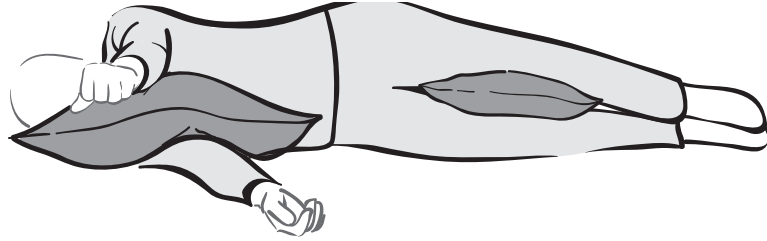
If you feel sore, numb or tingling

If surgery has irritated some of your nerve endings, you may feel sore or numb, or you may feel a tingling or burning on the back of your arm or in the area around your shoulder, under your arm and down your side and ribs. These feelings may increase a few weeks after surgery. Keep doing the exercises unless you notice an increase in swelling or tenderness. If this happens, tell your doctor. Sometimes gentle rubbing or stroking the area with your hand or with a soft cloth can help make it feel better.

Deep breathing

Deep breathing is an important part of your recovery and helps expand your chest wall. It helps with relaxation and can remind you to fill your lungs completely.

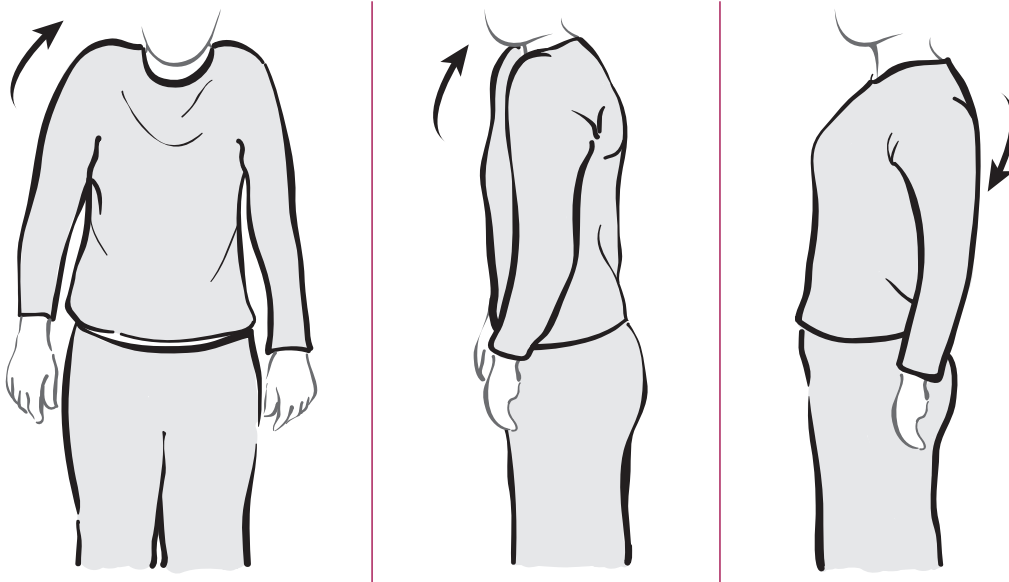
1. Lie on your back or sit in a chair and then take a slow, deep breath through your nose. Breathe in as much air as you can while trying to expand your chest and stomach like a balloon.
2. Do not tense your shoulders or neck.
3. Relax and breathe out slowly and completely.
4. Repeat 4 or 5 times.



- Sit in a chair with good back support and your arms supported by pillows. Repeat the exercise with hands and arms on both sides.

Shoulder shrugs and circles

This exercise can be done sitting or standing. It's a good warm-up exercise and can help relieve tension in your shoulders.



1. Lift both shoulders up toward your ears. Keep your chin tucked in slightly. Hold for 5 to 10 seconds, and then slowly drop them down and relax. Repeat 5 to 10 times.
2. Gently rotate both shoulders forward and up, and then slowly back and down, making a circle. Keep your chin tucked in slightly. Switch and repeat in the opposite direction.
3. Repeat 5 to 10 times in each direction.

Arm lifts

This exercise can be done sitting or standing. It helps improve movement in your shoulders.



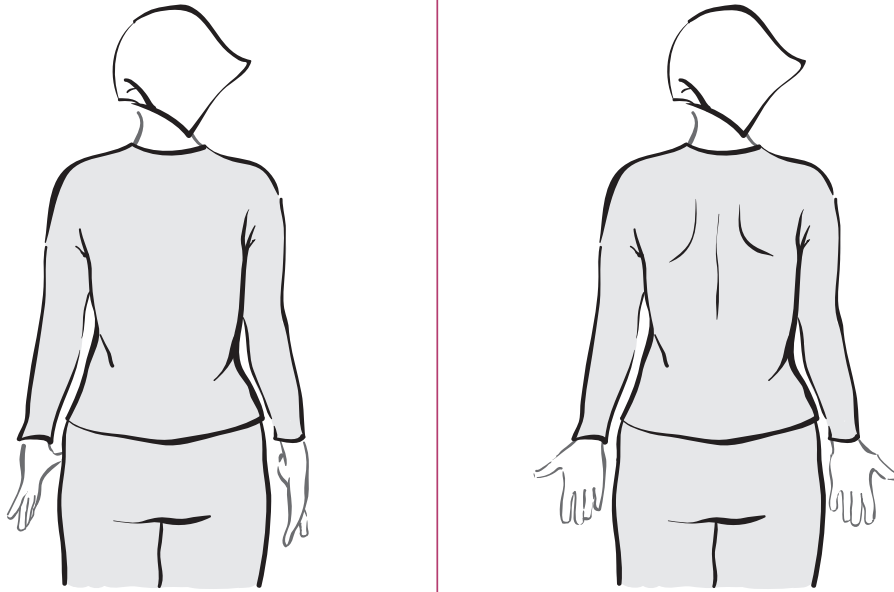
1. Clasp your hands together in front of your chest. Point your elbows out.
2. Slowly lift your arms upward until you feel a gentle stretch.
3. Hold for 1 to 2 seconds, and then slowly return to the start position.
4. Repeat 5 to 10 times.

If you need more support, grab your wrists with your hands instead of clasping your fingers.



Shoulder blade squeeze

This exercise helps improve movement in your shoulder and your posture.



1. Sit in a chair facing straight ahead without resting your back on the chair, or stand up. Your arms should be at your sides with your elbows straight and your palms facing your sides.
2. Open your chest, gently squeeze your shoulder blades together and down and rotate your thumbs so your palms face forward.
3. Hold for 5 to 10 seconds and practise your deep breathing while holding this posture. Relax and return to the start position.
4. Repeat 5 to 10 times.

Help reduce swelling after surgery

At the end of the day, or during the day when you have some time, prop your arm up on a pillow to help reduce swelling after surgery.

First stage of healing

The first 6 weeks after surgery

Starting your second week after surgery, or when your drain has been removed, it's important to try to get back the full use of your shoulder. Start with the exercises in this section, and do them 1 or 2 times a day. Once you are able to move your arms above your head more easily, move on to the exercises in the next section, Advanced Exercises for the First Stage of Healing. By the end of this first stage, you should have full movement of your affected arm and shoulder. But listen to your body. You shouldn't feel worse after the exercises.

Talk to your doctor or another member of your healthcare team before starting any of these exercises.

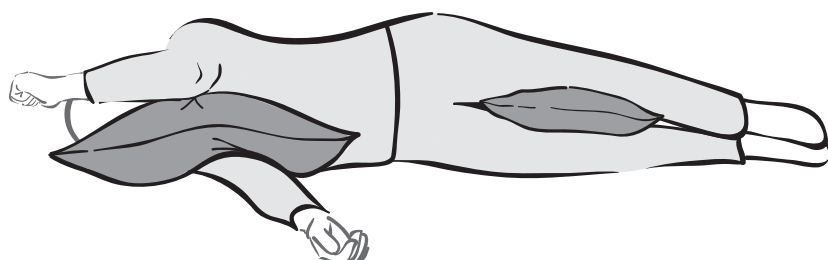
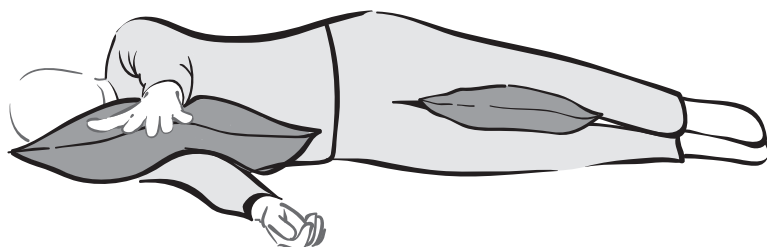
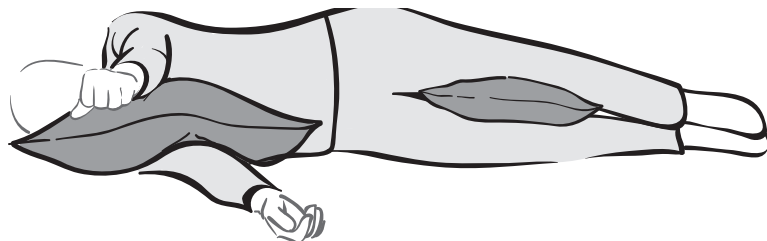
Avoid heavy lifting

During this stage of healing, don't lift anything heavier than about 5 kg (10 lb) – this amount may depend on the surgery you had.

As well as these exercises, keep doing the shoulder blade squeeze exercises that you were doing right after surgery.

Pump it up

This exercise helps reduce swelling after surgery by using your muscles as a pump to improve the circulation in your affected arm (on the same side as your surgery).

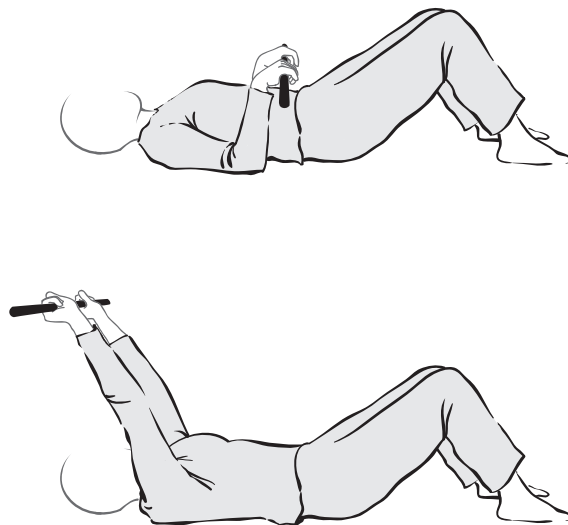


1. Lie on your unaffected side with your affected arm straight out, above the level of your heart. Use pillows if you need to. Or sit in a chair with good back support with your arm supported by pillows.
 2. Slowly open and close your hand. Repeat 15 to 25 times.
 3. Then slowly bend and straighten your elbow. Repeat 15 to 25 times.
- ✔ Sit in a chair with good back support and your arms supported by pillows. Repeat the exercise with hands and arms on both sides.

Wand exercise

This exercise also helps improve the forward movement of your shoulder. You will need a “wand” to do this exercise – try a broom handle, stick or cane.

Position 1



1. Lie on your back with your knees bent. Hold the wand with both hands. Your palms should be facing down, and your hands should be as wide apart as your shoulders.
2. Lift the wand over your head as far as you can until you feel a stretch. Your unaffected arm will help lift the wand.
3. Hold for 5 seconds. Lower arms.
4. Repeat 5 to 10 times.

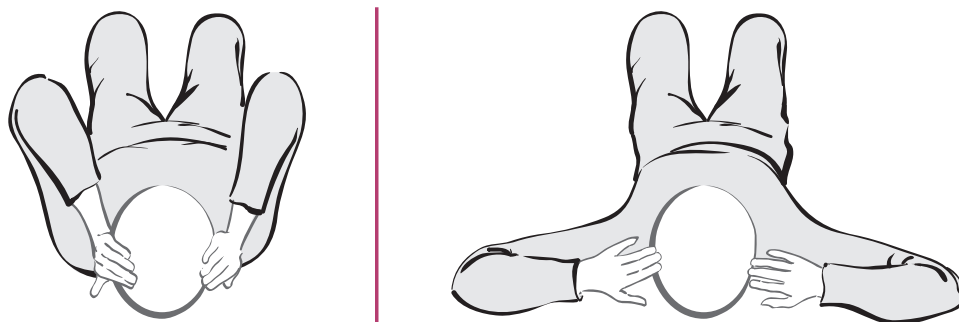
Position 2

Repeat with palms still facing down but hold the wand slightly wider apart than your shoulders.

- Place the wand on an angle so that the lower arm holds the bottom of the wand and helps the upper arm at the top of the wand to lift up. Repeat with the other arm at the bottom of the stick.

Winging it

This exercise helps improve movement in the front of your chest and shoulder. It may take several weeks of regular exercise before your elbows get close to the floor. If you feel pain or pinching in your shoulder, place a small pillow behind your head, above (not under) your affected shoulder.



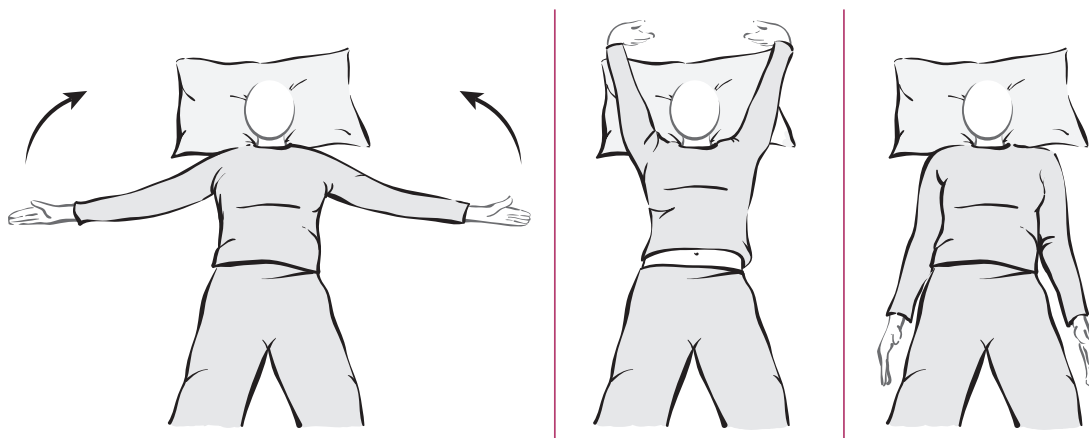
1. Lie on your back with your knees bent. Touch your fingertips to your ears with your elbows pointed to the ceiling. (If you can't comfortably put your hands at your ears, place your fingers on your forehead, palms facing each other.)
2. Move your elbows apart and down to the floor. Hold for 5 seconds.
3. Repeat 5 to 10 times.

If it's too hard to move your elbows down, place a folded towel on each side of the floor where your elbows will lower. When it starts to feel better, you can reduce some of the folded layers. Eventually the towels can be removed.

- ❖ If you start to feel pain while doing this exercise, it may be too much for you at first. Try doing one arm at a time instead.

Snow angels

This exercise helps to stretch the tight tissue in the armpit area and increases movement in your shoulders. It's OK to feel a gentle pull but if you start to feel pain or pinching, lower your arms and rest.



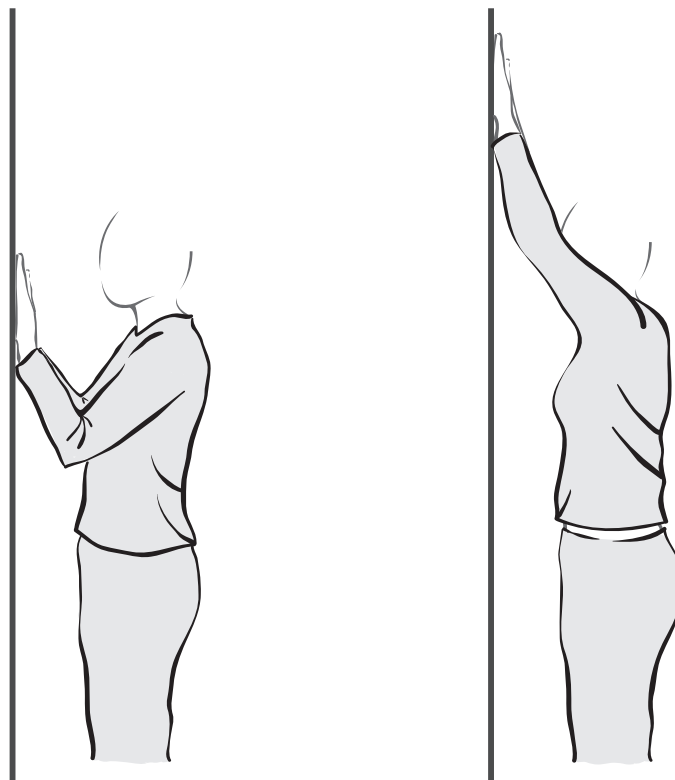
1. Lie on your back and extend your arms out at your sides.
2. Move them up over your head, leading with your thumbs, eventually touching your fingers at the top, and then move your arms back down to your sides (as if you're making an angel in the snow).
3. Repeat 5 to 10 times.

📌 If you start to feel pain while doing this exercise, it may be too much for you at first.

Try doing one arm at a time instead. Lift only as high as you feel comfortable, then slowly build up to the full position of lifting your arms over your head.

Wall climbing

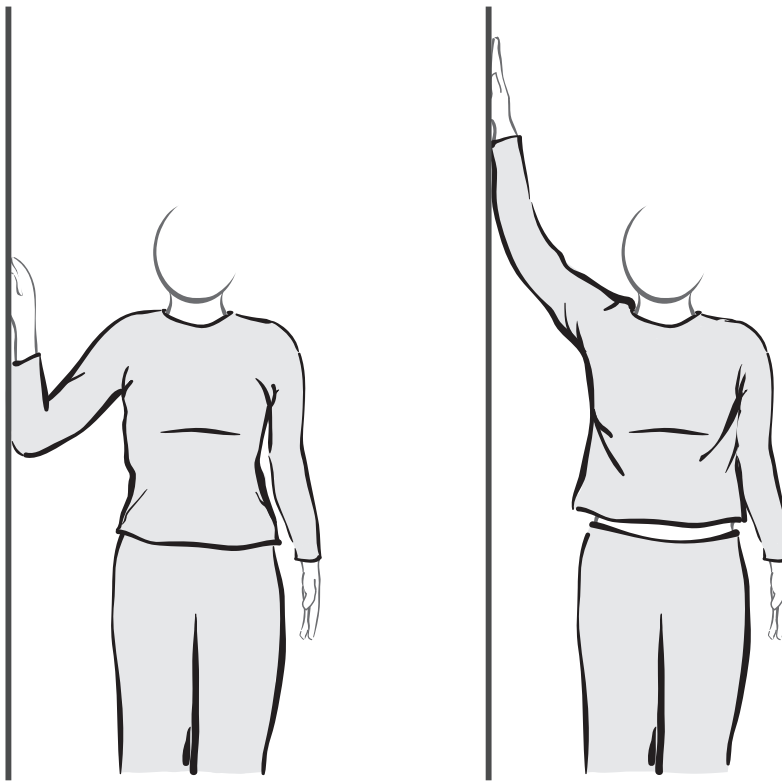
This exercise helps increase movement in your shoulder. Try to reach a little higher on the wall each day. This exercise can be done in 2 directions – facing the wall or with your affected side to the wall.



Facing the wall

1. Stand facing the wall, about 30 cm (12 in) away. Place both your hands on the wall at shoulder level. As you do this exercise, make sure you stand tall, keep your tummy tucked in and avoid arching your lower back.
2. Use the fingers of your affected arm to climb up or slide as high as you can go until you feel a stretch.
3. Return to the start position.
4. Repeat 5 to 10 times.

➤ Repeat this exercise with your other arm.



Side wall stretch

1. Stand with your affected side to the wall, about 60 cm (24 in) from the wall so you can touch the wall with your fingertips. Your arm should be just in front of your shoulder so you can see your hand on the wall in your side vision.
2. Walk your fingers up the wall or slide as high as you can go until you feel a stretch. Do not rotate your body toward the wall. Keep your torso facing forward even if it means you can't go up as high.
3. Return to the start position.
4. Repeat 5 to 10 times.

Avoid this exercise if you feel a pinch in the top of your shoulder when walking your fingers up the wall.

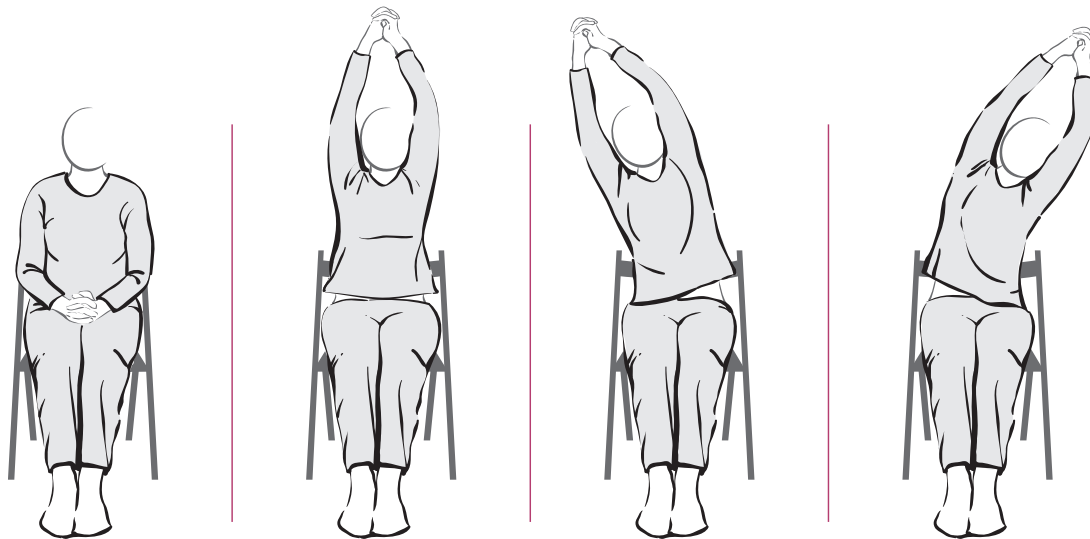
- Do this exercise first with one arm. Then turn around to face the other way and repeat with your other arm.

Advanced exercises for the first stage of healing

Once you're getting better movement in your shoulder, try these more advanced stretches.

Side bends

This exercise helps improve movement in your shoulder and chest wall on both sides of your body. You can do this exercise once a day.



1. Sit in a chair and clasp your hands together in your lap.
2. Slowly lift your arms over your head. Bend your elbows slightly.
3. When your arms are above your head, bend at your waist and move your body to the right. Hold for 5 seconds. Use your right hand to gently pull your left arm a little farther to the right. Keep yourself firmly planted on the chair. Take a deep breath in and out.
4. Return to the centre and then bend to the left, using your left hand to pull your right arm farther.
5. Repeat 5 to 10 times on each side.

Achieving full movement of your arm

Continue to do side bends every day until both arms are equally strong and can move easily. This may take 2 to 3 months or a bit longer if you've had surgery on both sides. You should be able to reach across the top of your head and touch your opposite ear without feeling a stretch in your underarm.

Other activities

It's safe to do light housework during the first 6 weeks after surgery. Do only short periods at a time and rest in between. You can start heavier activities after 6 weeks. Always let pain be your guide – a little discomfort is OK but more pain could mean you're doing too much.

Second stage of healing

From about 6 weeks after surgery

As you feel stronger, you can gradually start doing strengthening and general conditioning exercises. For some women, this means getting back to their old exercise routine, but for others it may mean trying out some new activities.

Talk to your doctor or another member of your healthcare team about starting a specific strengthening program or aerobic exercise, and ask if there are any special safeguards you should take.

If you have pain, your shoulder is tight or your hand or arm begins to swell, talk to your doctor or another member of your healthcare team.

Strengthening

You can keep building your strength by slowly getting back to household chores, gardening or yardwork.

Within 4 to 6 weeks after surgery, you can start doing your strengthening exercises with light weights of 500 g to 1 kg (1 to 2 lb). If you don't have any light weights, you can use an unopened soup can or a plastic bottle filled with water. Check with your doctor or physiotherapist to decide what weight is best for you. They can also suggest strengthening exercises for the upper body.

But it is important to build up slowly. If you don't exercise for several days, reduce the amount of weight slightly and build up again.

General conditioning

Regular aerobic exercise is any exercise that gets your heart and lungs working harder and improves your general physical condition. It can help with your recovery and has many benefits. It can help you:

- improve your cardiovascular fitness – how well your heart, lungs and blood vessels bring oxygen to your muscles – so that you can do physical work for longer periods of time
- maintain a healthy body weight
- feel better, which may reduce stress and anxiety
- face the challenges of life after cancer

Brisk walking, swimming, running, cycling, cross-country skiing and dancing are all examples of aerobic exercise.

Talk with your healthcare team about how much physical activity is right for you. Work toward being able to do 30 minutes of moderate activity most days of the week. But even if you can't do much at the beginning, a small amount of activity is better than none.

The “talk test” is a good way to see how hard you are exercising. If you are able to talk but not sing during the activity, it is moderate activity. If you are not able to say more than a few words at a time without pausing for a breath, it is vigorous activity.

Axillary web syndrome (cording)

In the weeks soon after surgery, some women have pain that feels like a tight cord or cords pulling from their armpit down their arm. This is called axillary web syndrome (AWS), or cording. AWS appears as tender, cord-like structures below the skin in the armpit area and down the arm. Sometimes they extend as far as the wrist. If you have cording, it might be hard to reach for objects overhead, lift your arm or straighten your elbow.

We don't know the exact cause of cording. The cords may be part of the lymphatic system or small veins that have been damaged during surgery.

If you get cording, keep doing your daily stretching to the point of feeling tension but not pain, and contact your physiotherapist. In most cases, cording goes away on its own over time.

Lymphedema

As part of your ongoing recovery following surgery, you should be aware of the possibility of lymphedema and act quickly if you notice any signs of swelling. Lymphedema is swelling in the affected arm, hand or chest wall caused by a buildup of lymph fluid. The swelling happens because lymph nodes, which normally act as filters, aren't able to do their job as well because they've been removed by surgery or they've been damaged by radiation therapy or the cancer itself. Lymphedema is different from the temporary swelling in the breast, armpit and arm that can happen just after surgery.

Lymphedema can happen soon after treatment, months later or even years later. It can be temporary, it can come and go or it can last a long time. It's easier to manage if you get help for it early.

Watching for signs of lymphedema

The start of lymphedema can be hard to notice, but it's very important to treat it quickly. Tell your doctor right away if you notice swelling in your hand, arm or chest wall – even if it happens years after treatment. Some other signs to watch for are:

- feeling of fullness, puffiness or heaviness in your arm
- decreased flexibility of movement in your hand, wrist or arm
- jewellery (including watches) feeling tight even though your weight hasn't changed
- problems fitting your arm into your sleeves
- redness or increased warmth, which may mean that you have an infection

Ways to reduce your risk of lymphedema

One of the most important ways to reduce your risk of lymphedema is to maintain a healthy body weight. If you are overweight, you have a greater chance of getting lymphedema, and it may be harder to control or treat.

Here are some other ways to reduce your risk of lymphedema.

> **Tips**

- Take special care of your skin and keep your arm moisturized. Try to avoid breaks in the skin that could lead to infection.
- Stay out of direct sunlight, and wear sunscreen to avoid sunburn, especially on your arm and chest.
- Wear insect repellent to avoid bug bites.
- Do not cut the cuticles back when you manicure your hands. Push them back.
- Be careful when shaving under your arm.
- Use your other arm to have blood samples or your blood pressure taken, or for injections, if possible.
- Wear work gloves when gardening or doing other outdoor chores.
- Wear loose-fitting gloves when working with household cleaning products or when your hands are in water for a long time.
- Use a thimble when sewing to protect your fingers from getting pricked by needles or pins.
- Treat infections in the arm on the same side as your surgery as soon as possible. Your doctor may suggest you keep antibiotics at home, just in case.
- Avoid using the arm on the same side as your surgery to lift or carry anything heavy, such as heavy groceries, unless you've built up your strength to do this.

- Exercise regularly, but don't overdo it in the early weeks after surgery. Moving your arm and contracting the muscles as you exercise helps move fluid through your arm. Talk to your doctor about the right exercise for you. Increase your exercise gradually, and watch how your body responds.
- Avoid tight-fitting cuffs, watchbands, bracelets and rings, and tight or narrow bra straps. They may prevent the fluid from flowing away from the area and may lead to swelling.

Ways to manage lymphedema

One of the best ways to manage lymphedema is to wear a compression sleeve. Here are other things to consider when you have lymphedema.

> Tips

- Be careful using saunas, steam baths and hot tubs. Some women find that heat can make lymphedema worse.
- Travel with care. Some women find that their lymphedema is worse when they travel a long distance in an airplane (over 4 hours) or when arriving at a hot climate. If you have a compression sleeve, your healthcare team may suggest you wear it when flying.
- Keep your arm moisturized. This helps keep the skin supple and prevents it from becoming dry and cracked especially in winter.
- Wash the area well with soap and water if you get a cut or burn on your arm or hand. Keeping it clean is also important. Your doctor or pharmacist may suggest an antibacterial cream or ointment.

Canadian Cancer Society

We're here for you.

When you have questions about treatment, diagnosis, care or services, we will help you find answers.

Call our toll-free number **1 888 939-3333**.



Ask a trained cancer information specialist your questions about cancer.

Call us or email info@cis.cancer.ca.



Connect with people online to join discussions, get support and help others.

Visit CancerConnection.ca.



Browse Canada's most trusted online source of information on all types of cancer.

Visit cancer.ca.

Our services are free and confidential. Many are available in other languages through interpreters.

Tell us what you think

Email cancerinfo@cancer.ca and tell us how we can make this publication better.

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What we do

The Canadian Cancer Society fights cancer by:

- doing everything we can to prevent cancer
- funding research to outsmart cancer
- empowering, informing and supporting Canadians living with cancer
- advocating for public policies to improve the health of Canadians
- rallying Canadians to get involved in the fight against cancer

Contact us for up-to-date information about cancer and our services or to make a donation.



Canadian Cancer Society Société canadienne du cancer

1 888 939-3333 | cancer.ca
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Breast Cancer Surgery

- ☐ Breast Lumpectomy
- ☐ Partial Mastectomy
- ☐ Simple or Total Mastectomy
- ☐ Modified Radical Mastectomy
- ☐ Axillary Lymph Node Removal
- ☐ Sentinel Node Biopsy

Contact your general surgeon the day after your surgery to make a follow-up appointment.

Date of follow-up appointment with surgeon:

This pamphlet outlines the care you will receive while in hospital. Each person is different so your treatment plan may be slightly different than the one outlined here. The nurses, doctors and health professionals caring for you will be available to review this information with you and answer any questions you may have.

Different types of breast cancer surgery

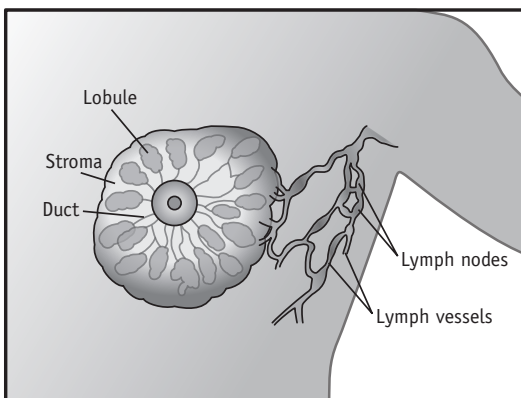
Partial mastectomy/Lumpectomy is the removal of a small amount of breast tissue containing the cancer plus some of normal breast tissue around it.

Simple or total mastectomy removes the breast, with its skin and nipple but not lymph nodes in the armpit.

Modified radical mastectomy removes the breast, nipple/areola and underarm (axillary) lymph nodes or glands.

Axillary lymph node dissection is the removal of some the lymph nodes in the armpit.

Sentinel node biopsy. When breast cancer cells escape from the tumour in the breast they travel to the lymph nodes under the arm, the first lymph node they reach is the “sentinel” node. If the sentinel nodes do not contain cancer cells, this may eliminate the need to remove additional lymph nodes.



General Information

You will be staying in the hospital for one night and will be ready to go home when:

- you are medically stable
- your pain is managed with oral pain medicine
- your nausea is treated
- you are able to walk
- we highly recommend you have someone stay with you for the first night after your surgery

Date of Surgery _____

Time of Surgery _____

Name of Surgeon _____

☐ UBC Hospital

☐ Vancouver General Hospital

What to expect after your surgery

During and after your surgery, you will be given medication to help control pain and nausea. These medicines may be given to you in your intravenous (a small tube in your arm), by injection, as suppository or in pill form.

Your nurse will regularly check your:

- Blood pressure, pulse, breathing, temperature and oxygen levels
- Bandage on your incision site
- Level of pain
- Nausea and ask you if the medication is helping to decrease the nausea

You will be encouraged to take deep breaths and move your feet.

When you are able to drink clear fluids without feeling nauseous (sick to your stomach), you may start to eat solid food.

Let the nurse know if you are nauseous and you will be given medication.

Pain Control while in hospital

The nurses will ask you to rate your pain by using a pain scale 0 to 10 (0 being no pain up to 10 being terrible pain). Pain can prevent you from moving, deep breathing and sleeping, all of which could slow your recovery. They will also show you ways to decrease and cope with the pain.

When you are ready to go home

The nurse will explain the home instructions in this pamphlet and arrange for homecare nursing if needed before you leave.

What medications do I take for pain at home?

You may have pain, numbness, swelling, or tingling along the wound site, chest area or arm (if you had axillary nodes removed) for a few days to a few weeks after surgery.

Take the pain medicine your surgeon prescribed. If the pain is mild to moderate, you may prefer to take plain or extra strength acetaminophen (Tylenol). Some pain medicines can make you drowsy, therefore, do not mix with alcohol and avoid driving.

Do not take aspirin for pain as it may cause bleeding. If your pain worsens or does not improve, call your surgeon.

What food should I eat?

Some pain medication will cause constipation. To prevent constipation eat fruit, vegetables and whole grains to help your bowels to work. You may also use a mild laxative (available from your pharmacist).

Drink plenty of fluids (unless you have kidney failure or heart disease—discuss this with your doctor).

A well-balanced diet is important for wound healing.

How do I care for my wound?

Your wound may be open to air and held together with small tapes (steri-strips), stitches (sutures) that dissolve or staples. It takes about three weeks for the stitches to dissolve and the wound to heal.

- If you have stitches that do not dissolve or staples, these should be removed in 5-7 days after your surgery.
- If you have steri-strips **do not** remove them, they will eventually fall off. There is no need to replace the steri-strips once they have fallen off.

There may be some bruising, tenderness and perhaps some slight bleeding around the wound site. Numbness in the arm is also common. This is normal and will improve over time.

You may shower 24 hours after the drains are removed.

Once the drains are removed, keep the wound clean by showering every day. Gently pat the wound dry with a clean towel; do not rub the area.

Avoid tub baths until your wound is fully healed. Soaking in the tub may increase the risk of infection.

If you have had an axillary node dissection, your wound has healed and you wish to shave your underarm- we recommend you use an electric razor rather than a straight razor. This will prevent cuts while shaving.

Do not use deodorant or antiperspirants under your arm until the wound is healed.

Some surgeons believe that the scars may be improved by applying tape to them for about three months after the surgery. If this is something you would like to do, put 3M Micropore (available in drug stores) one-inch paper tape along the length of the scar.

It is recommended that you **do not put Vitamin E on the wound lines**. Some surgeons believe this may widen the scars.

How do I care for my drain at home?

After surgery it is normal for your body to make extra fluid in the area where the surgery took place. A drain (small plastic tube) is sometimes put in by the surgeon to remove the fluid.

Your surgeon may refer you to homecare nursing if you go home with drains. They will help you manage the drains and/or dressings and any other health problems you may have once you are home. You will need to record the amount of drainage from each drain.

Before you go home, the nurse will teach you how to empty the drain and stop the tubing from being blocked (stripping the tubing). You can wear the drain under your clothing pinned at the waist level.

You will be given written instructions about drain emptying and stripping. It is important to make sure the drain is not blocked to prevent the collection of fluid inside the wound area. If fluid is not coming out of the drain, tell the homecare nurse or your surgeon if you do not have a homecare nurse.

Your surgeon or homecare nurse will remove the drain when drainage has decreased usually less than 20-30 cc's drainage per day for each drain. This can be a slow process varying from person to person. Some fluid may leak from the opening after the drain is removed. If that occurs, cover the area with sterile gauze.

How do I keep the Drain clean?

- Rinse the measuring container with hot water after each use.
- Empty the drain when it is half full.
- Drainage is often pink- then becomes yellow to clear.
- If the chamber falls off, rejoin it to the tubing. Recompress the drain to activate it.
- If the drain does not remain compressed, take it apart and rejoin it a number of times. Use tape if necessary.

What is a seroma?

After the drain is removed, fluid may build up and you may develop a pocket of fluid called a seroma.

The body may absorb seromas if they are small, but if they are large, the surgeon may need to remove the fluid. This procedure is done in the surgeon's office and may have to be repeated several times.

What should I wear after surgery?

After Partial mastectomy (lumpectomy)

It may help to wear a support bra after surgery. This can also be worn while sleeping. Cotton "sport bras" offer comfort. Look for a front closure. The less elastic, the better! Armholes should be cut low under the arm. Some women prefer a simple cotton undershirt, camisole or tank top. These may come with a built in "Shelf" bra. Some women prefer not to wear a bra. It is a matter of choice and comfort.

After Mastectomy

The wound is healed when the pain and swelling of the mastectomy has settled (usually 4-6 weeks after surgery). Cotton breast forms ("temporary puffs") may be worn in your bra during the first couple of weeks. The Canadian Cancer Society Cancer Information Service provide "temporary puffs" for free. You may then be fitted with a permanent prosthesis. They also have a list of mastectomy shops in your area.

Call 1-888-939-3333 for more information.

What activities can I do?

Light exercises such as walking will help you recover.

As you feel stronger, you will be able to take longer walks and increase your activity level.

You may lift objects that you can manage easily. For 4 weeks after lymph node removal, lift no more than 5 pounds on the side of the surgery.

Each person recovers differently so check with your surgeon about your activity level. In most cases, you can return to normal activity as soon as you feel ready.

What exercises should I do at home?

Your exercises are on page 15.

Exercising your arm may be painful at first but it will become less so as time goes on.

Use your arm for normal daily activities such as gently brushing your hair/teeth and washing yourself.

Avoid activities that strain your arms, shoulders, or chest area such as vacuuming, heavy lifting (including children), ironing, carrying things over the shoulder on the side you had your surgery and push-ups.

Your surgeon will discuss any further limits to your activities. Each person responds differently.

When can I return to work?

The time it takes to recovery depends on your health and the type of surgery you had. Most women are able to return to work within two to four weeks. However, some women have fatigue for a number of months.

Call your surgeon if any of the following occurs

- Wound drainage has stopped, then started again or a noticeable change in the type of drainage (bright bleeding or foul-smelling).
- Green/yellow drainage from the wound or drain site.
- Increased redness and/or heat around the wound, or change of colour over the breast
- Increased or constant pain that is not relieved by prescribed pain medication.
- New swelling of your breast or your armpit.
- Chills, fever, a temperature more than 38.5°C (101.3°F) when measured by mouth.
- A seroma has formed after the drain is removed.
- You cannot stop being sick to your stomach (vomiting).
- You are not able to drink **anything** for 24 hours because you feel too sick.
- You have redness or aching in your calves and/or swelling of your leg.

If you cannot reach your surgeon, you need to contact another doctor (family doctor, walk-in clinic, urgent care centre or emergency department).

Call 911 or other emergency services if you have sudden, severe chest pain or shortness of breath.

Coping with your emotions

Women with breast cancer may experience many emotions ranging from anger, anxiety, fear, despair or hope, sadness, depression or acceptance.

Each person's recovery is individual, and there is no right or wrong way to cope with it. Many women with breast cancer cope by sharing their worries and feelings with family and/or friends. Other women cope by attending support groups. Allow friends and family to help with practical things like meals, laundry, shopping.

If you would like to know about patient and family counseling services contact the **BC Cancer Agency** Counseling Service 604-877-6000 local 2194

Call the **Canadian Cancer Society** information line at 1-888-939-3333 if you feel that:

- learning about your condition will help relieve your anxiety and fear of the unknown or
- you would like information about support groups or
- you would like to be connected with someone who has gone through something similar to you (Cancer Connection Program)

Do I need to have a mammogram or do breast self-examination?

We encourage you to continue with screening mammography after age 40 (annual/biannual) and annual clinical breast examinations.

Monthly breast self examination (BSE) is no longer recommended.

What is lymph edema?

Lymph nodes (glands) in the armpit are sometimes removed during breast cancer surgery (axillary dissection). These nodes can give important information about how far the cancer has spread.

Some swelling in the breast and arm area is normal during the first few weeks after axillary node dissection.

If you have ongoing tightness, aching/pain, heaviness, swelling, redness, less movement/flexibility of your arm, hand or wrist you may be developing a condition called lymphedema and should report these symptoms to your doctor.

For further information about lymphedema call the Cancer Society information line at 1-888-939-3333.

The following recommendations may help to reduce your chances of getting lymphedema:

- After surgery, position your arm on a pillow. Keep the arm raised above the level of the heart for 45 minutes two to three times a day while lying down.
- It is important to prevent infection as this could lead to lymphedema. Wash cuts, scratches or burns promptly, treat them with antibacterial medication and cover them with a bandaid.
- Use insect repellent or wear long sleeves when possible to avoid insect bites.
- If signs of infection occur after injury or insect bite (redness, pain or swelling) see your doctor for treatment as soon as possible.
- Avoid getting sunburn on the arm, use sunscreen or protective clothing.
- Wear gloves when gardening or oven mitts when reaching into the oven or barbecuing.

- Have blood drawn, intravenous lines, injections or blood pressure measurement on the opposite arm if possible.
- Use an electric razor with a narrow head for underarm shaving.
- Maintain a balanced diet and ideal weight.
- It is important to use your arm in the activities of daily living.
- Talk to your Doctor about the need to use compression stockings when going on a plane.

When your surgeon says you are ready, you can include swimming and other activities to stimulate lymph drainage.

What is axillary web syndrome (lymphatic vessel cording)?

After axillary node dissection and/or radiation treatment to the axilla, a condition known as “axillary web syndrome”, hardening of the lymphatic vessels may occur. This condition is described as a stiffness or tightness in the underarm, forearm and wrist.

Fine cords (like violin strings) running down the inside of the arm and sometimes into the forearm may be noticed. Previously gained range of motion may be lost.

Axillary web syndrome usually resolves without treatment within weeks or months.

It is not recommended that the cords be snapped but rather slow prolonged stretching to maintain shoulder and elbow range is important.

Physiotherapists who provide breast cancer rehabilitation maybe consulted. Call the Cancer Society’s information line at 1-888-939-3333.

Summary

The information in this booklet comes from the voices of many women who have shared with us their experience of breast cancer surgery. The nurses, doctors and physiotherapists who care for these women compiled this booklet.

We welcome comments about the content and format of this booklet. If you would like to contribute to the booklet or have suggestions for improving the content or format, please speak to your nurse, doctor or call the Centre for Patient's and Families at 604-875-5887 or email: centreforpatients@vch.ca

Besides the information in this pamphlet, also remember:

Exercises after Mastectomy and Axillary Node Dissection

Stiffness of the back, shoulder and arm may be felt after breast surgery. To get back full movement it is very important to **exercise**.

Start your exercises the day after your surgery and continue until you are using your arm normally in household duties and other activities.

Goals of Exercise

- to get back full use of your arm and shoulder
- to keep swelling down
- to have good posture
- to relieve stress and anxiety that sometimes come with surgery
- to help you in getting back to normal activities as soon as possible

Exercises

- Each exercise is to be done 3–5 times daily.
Repeat each exercise 10 times, unless instructed to do otherwise.
- Do the exercise until you feel a gentle stretch.
- Do your exercises in front of a mirror, if possible and check for equal arm movements.
- Do not make any quick, jerky movements or push into pain.
- Abdominal exercises will be started when your plastic surgeon feels you are ready (approximately two months after surgery).
- It is normal to have some discomfort with exercise but if you have significant increase in pain or swelling contact your doctor.

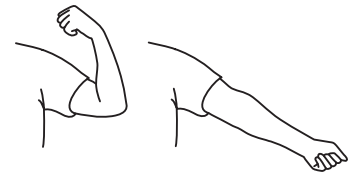
Exercises to begin the day after surgery

1. Hand pumps and elbow bends

a) Make a fist and then stretch fingers straight.

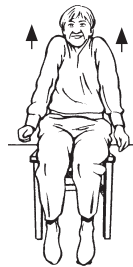


b) Bend and straighten your elbow.



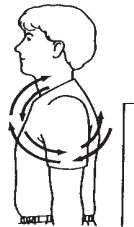
2. Shoulder shrugs

Shrug shoulders up to your ears.
Relax and let them down.
Breathe in when you lift and breathe out when you lower.



3. Shoulder circles

Roll shoulders backwards.
Repeat, rolling shoulders forward.



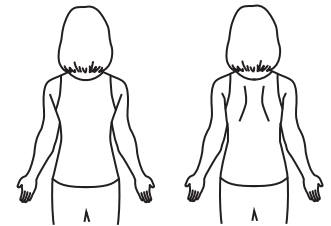
4. Neck stretch

Tilt head to one shoulder to stretch opposite side of neck and hold for 5-10 seconds. Repeat to opposite side.



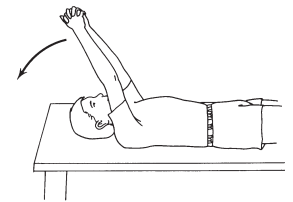
5. Shoulder blade squeeze

Sit or stand with your arms by your sides and your palms facing your sides.
Gently squeeze your shoulder blades together and down.
Hold for 5–10 seconds then relax and return to the start position.



6. Arm lifts

Clasp hands and raise arms overhead, keeping elbows straight. Lower slowly.
Begin in lying position and progress to sitting.



Exercises to add in at Week 2

7. Winging it

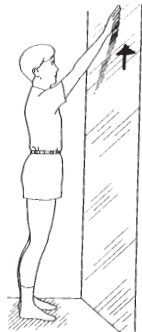
Lie on your back and touch your fingertips to your ears with your elbows pointed to the ceiling.

Move elbows apart and down to the bed, hold 2 seconds and then bring them back up to starting position.



8. Wall walking

- Facing a wall, “walk” fingers up the wall as far as you can. “Walk” back down. (Both arms)
- Stand sideways to a wall, and “walk” fingers up as far as you. “Walk” back down. (Affected arm)



9. Snow angels

Lie on your back with your arms at your sides and elbows straight.

Move your arms out and over your head and then back to your sides.



How long do I need to do these exercises for?

Continue these exercises until both arms are moving equally easily. This may take 2–3 months.

From 6 weeks onwards

As you feel stronger you can gradually start increasing your physical activity and strengthening exercises. It is important to build up slowly. You may want to consult your doctor or physiotherapists to help you plan a suitable program

Physical activity (eg walk, bike, swim, aerobics and yoga)

There isn't one activity or sport that is better than another. What is important is keeping active. Find what you enjoy and make a plan to allow you to gradually get into or go back to the activity.

Aim for 150 minutes of aerobic activity a week.

Physical activity will help you maintain a healthy body weight and prevents many chronic diseases. It will also keep your arm strong and moving well and will help you control swelling in the arm.

Strengthening

Some ways to keep building strength:

- Slowly getting back to household chores, gardening or yard work.
- Exercises with light weights (1-2 lbs), if you don't have weights you can use unopened soup cans or filled water bottles.

Posture

It is important to maintain good posture after your surgery. In front of a mirror, check that your chin is tucked in, your shoulders are level and pulled back, and your spine is straight.

Hand and Arm Care

- Keep swelling down by elevating your arm above your heart for 20–30 minutes (on pillows, the back of a couch, etc.) and pump your hand intermittently.
- Alternate arm activity with rest and elevation for the first few days after surgery.
- Carry heavy objects such as shopping bags, briefcases and luggage on the side you did not have surgery.
- Do not use heating pads, hot water bottles or ice packs over your incision as your skin sensation is less in this area and you won't feel if it is too hot or cold. (Ice packs can be used if you did not have a mastectomy.)
- Daily activities are good arm exercises. Use your affected arm for grooming, eating, light housework and hobbies. But don't force it.

Swelling, Injury, Excessive Pain

Report these to your doctor or Emergency Department immediately.

Please contact your doctor if you do not understand these instructions.

Appendix

HealthlinkBC- Dial 8-1-1 24 hours per day
www.healthlinkbc.ca

Counselling Services

BC Cancer Agency Patient & Family Counselling Services (free)
604-877-6000 local 2194 or 1-800-663-3333

Cantonese/Mandarin speaking counselling (free)
Call Sandy Kwong MSW: 604-877-6098 local 2375
at the BC Cancer Agency

Breast Cancer Information

Cancer Information Service
604-675-7148 or 1-888-329-3333

B.C. Cancer Agency Library Services
604-877-6000 local 2688 or 1-800-663-3333

Internet Sites

BC Cancer Agency	www.bccancer.bc.ca
Abreast in the West	www.abreastinthewest.ca
BC HealthGuide Online	www.healthlinkbc.ca/healthguide.stm
Breast Reconstruction	www.vch.ca/breastreconstruction

Reference Materials

Love, S. (2010). Dr. Susan Love's Breast Book 5th Edition
Reading, Massachusetts: Addison-Wesley Publishing Company.

Olivotto, I., Gelmon, K. & Prithchard, K., 5th Ed. (2006).
The Intelligent Patient Guide to Breast Cancer: All you need to know to take an active part in your treatment.

BC Cancer Agency Patient Teaching Pamphlet Getting Ready for Breast Cancer Surgery (2010)

For more copies, go online at **<http://vch.eduhealth.ca>** or
email **pchem@vch.ca** and quote Catalogue No. **FE.323.B741**
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www.vch.ca

Functional Rehab After Breast Cancer Surgery



Princess Margaret



A guide for patients who had a Lumpectomy, Mastectomy, Sentinel node biopsy or Axillary node dissection

Read this information to learn:

- how you can expect to feel
- what daily activities you can do
- what exercises to do after your surgery
- how scar massage can help
- other helpful resources

Please visit the UHN Patient Education website for more health information: www.uhnpatienteducation.ca
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Author: Stephanie Phan, Registered Occupational Therapist
Revised: 02/2015
Form: D-5590



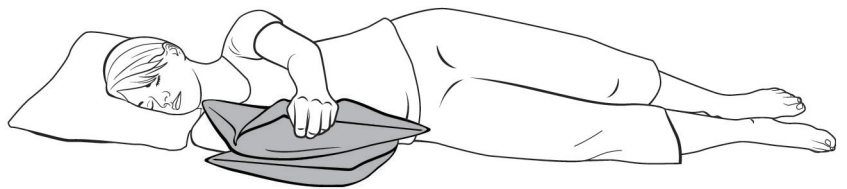
Learning how to care for yourself will help you feel better and get back to your normal activities sooner.

How can I expect to feel?

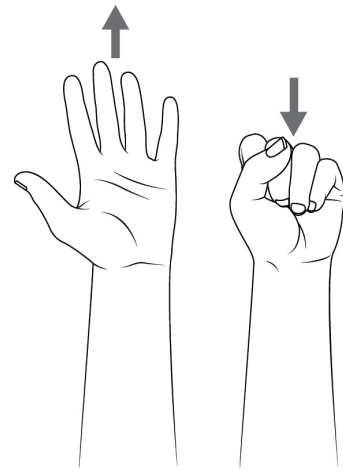
Pain or numbness

After your surgery, you may have sharp pains, feel pins and needles or be more sensitive on the side of your body where you had your surgery.

You may also feel numb (have no feeling) at or near the area where you had the surgery. This should get better as your nerves heal.



- Raise your arm and slowly open and close your fist 10 times. This acts like a pump and helps drain fluid out of your arm.



If you had axillary node dissection, some common side effects are:

- swelling of your arm
- limited movement of your arm and shoulder
- numbness of your upper arm skin

Some patients may develop cording and lymphedema.

Cording (also called axillary web syndrome)

You may feel thick cords (like ropes) under your skin in your armpit that run down into your arm. This is sometimes a side effect after sentinel lymph node biopsy or axillary node dissection. The cords tend to be tight and painful. They can make it hard to lift your arm, straighten your elbow or reach for things over your head.

Cording usually goes away over time with regular stretching and exercise. But, it's important to talk to your doctor if you have this side effect.

Lymphedema

Lymphedema is a build up of fluid in a body part caused by damage to your lymphatic system. If your lymph nodes are damaged or missing, they can't properly drain an area of your body. This causes fluid build up and swelling in your tissues.

Your lymphatic system can become damaged if:

- lymph nodes were removed during your surgery
- you had radiation to an area where lymph nodes were removed

If you had treatment for breast cancer, lymphedema may happen in your hand, arm, shoulder, breast, chest, or middle of your body.



Talk to your doctor if tightness or swelling in your arm or breast area doesn't improve within 4 to 6 weeks.



What activities can I do?

During the first week you are home from the hospital, try to get back to your usual activities. Use both your arms, if you can. For example:

- Use your arm (surgery side) to brush your teeth, comb your hair, eat and dress yourself.
- Move your elbow and hand as much as you can.
- Try to circle your shoulder and turn and tilt your head. Move your shoulder as you would normally, but only as far as you can without feeling pain.
- Start doing stretches when your drain is removed. Continue doing stretches until you can move your arm normally again.

If you try a new activity and it causes pain or discomfort, wait a week and try it again.

You can expect to feel tired at first. Taking rests in between your activities will help. Accepting help from your family and friends can also help.



Don't lift anything more than 10 pounds (5 kilograms) **for 4 to 6 weeks after your surgery**

Don't do any movements that are tiring and repetitive like vacuuming or scrubbing **until your drain is removed.**



Showering

For the first 2 days after surgery, you may have a shower or a sponge bath. But, it is important to **keep the area where you had the surgery dry.**

If you don't have a drain:

- Remove the outer gauze bandage 48 hours after your surgery. You can then take a shower.
- Don't let the shower stream go directly on your incision (cut) area. Let the water gently run over the area instead.
- When blow-drying and styling your hair, it may be more comfortable at first to support your arm with something, like a telephone book.

If you have a drain:

- Keep the area where the drain goes into your body dry. Cover it with plastic, such as plastic wrap and tape.



Dressing

To help make dressing easier:

- Wear loose fitting tops that close at the front for the first few weeks.
- If you have trouble moving your shoulder, dress that side of your body first and undress that side last.
- To put on a bra with clasps, start by fastening the bra in front of you then turn it around. As your shoulder improves, try to reach behind your back to fasten it.



Driving

You must be able to turn and move without any sharp pains before it's safe for you to drive. Wait until you no longer need to take prescription pain medicines before you drive. Always wear your seat belt, even if it causes some discomfort across your chest.



Don't drive if you are taking any medicines that make you feel drowsy.



Work

Everyone recovers differently. You may need some time off work. Talk to your doctor about the best time to return to work.

Saving your energy

Recovering from surgery can take up a lot of your energy. This is normal, but it can be hard when you want to do things. Don't try to do everything. Do the activities that are most important to you, and ask for help when you need it.



Follow these tips to save energy while you recover:

- Pace yourself** → Don't schedule too many activities in 1 day. Spread them out during the day and week. Give yourself enough time to finish an activity without having to rush.
- Plan ahead** → Gather all the things you will need before you start an activity. Keep things close to you, especially if you use them often. You won't tire as easily if you are organized.



Use aids

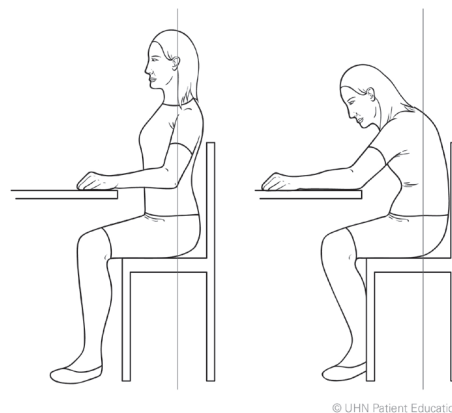
- Use things to make it easier for you to do things, like appliances to chop or mix food or a long handled dust-pan to help clean.

Rest often

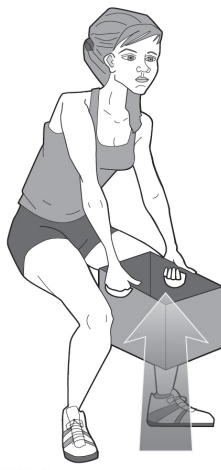
- Sit when you can. Don't wait until you are tired before you rest. Plan rest times throughout the day, for example, 5 to 10 minutes each hour.

Keep your back straight (good posture)

- Sit and stand straight. This balances your muscles and decreases stress. Bending your back forward makes it harder for you to breathe deeply.



Use good body mechanics



- Using good body mechanics means moving your body in a way that will make doing things easier and safer.

For example, push or pull rather than lift. Slide things along a counter and stand close to something you want to move. Always carry things close to your body. If you must lift, use your larger leg muscles rather than the smaller muscles of your back.

What exercises should I do after surgery?

Here is a list of exercises to do as part of your recovery. They can help reduce many of the side effects of your surgery and help you get back to doing your normal daily activities faster. These exercises are also important to help keep your arm and shoulder flexible if you have radiation therapy.

Deep breathing

Deep breathing is easy to learn, and you can practice it almost anywhere.

It can help:

- with your exercises and make it easier to relax
- keep your lungs clear
- reduce your pain
- lower or control your stress or anxiety (worry)

How to do deep breathing:

1. Find a comfortable position. Sit in a chair or lie face up.
2. Take a slow deep breath in through your nose.
3. Let your chest and belly expand. Do not let your shoulders rise up toward your head as you breathe in.
4. Breathe out slowly through your mouth. Repeat this as many times as you like.



You may find the Yogic Breathing Exercises video to be helpful when practicing deep breathing. Visit the website:

 <http://youtube.com/user/UHNPatientEducation>

Relaxation exercises

Relaxation exercises can take time and practice to learn, but they can:

- reduce any anxiety you may have
- increase your energy
- improve your concentration
- increase your self-confidence
- prevent stress from building up



Relaxation exercises include things like:

- **Progressive Muscle Relaxation**
You tense or tighten and then relax different muscle groups in your body.
- **Guided Imagery**
You use your imagination to focus on calm and peaceful images in your mind.

For more information, check the Patient Education calendar for drop-in relaxation sessions at Princess Margaret Cancer Centre or in your community. You can also find more resources in the Patient Education Library or at the websites:

 www.innerhealthstudio.com/

 www.helpguide.org/home-pages/emotional-health.htm

Walking

It is important to continue walking after surgery and during your recovery. Walking is a great way to improve your strength and endurance after surgery. It also improves your circulation (the blood flow) in your body. This helps with healing. Start slow and rest often until you are able to return to your normal level.



If you have some pain when walking, you can support your arm by keeping your hand in your pocket. As your pain decreases, return to swinging your arm by your side.

Exercises to improve the movement of your shoulder

It's important to start moving your arm on the side you had breast surgery as soon as possible after surgery. This will help prevent scar tissue from forming. Too much scar tissue could reduce the movement in your shoulder. Moving your arm and doing exercises will also help you return to your daily activities sooner.



Follow this important guide for doing these exercises, so you can stay safe:

Get back the full range of motion in your shoulder

In the first 6 weeks after surgery, your goal is to get back the full range of motion in your shoulder. Full range of motion means being able to move your arm and shoulder the same way you did before your surgery.

If you get your full range of motion back before 6 weeks, include stretching exercises as part of your exercise routine. This is especially true if you feel a stretch in your chest or under your arm during certain exercises. The exercises will help prevent scar tissue from forming that can get in the way of your range of motion later.

After you get back the full range of motion in your shoulder, your goal is to make your arm stronger. Start with light weights (about 2 to 3 pounds) or a light resistance band. Progress slowly.



If you do not get back to full range of motion in your shoulder after 6 to 8 weeks, contact your doctor. They may refer you to the **Function and Mobility Clinic** at Princess Margaret Cancer Centre.

If limited shoulder movement is keeping you from starting your radiation therapy treatment, ask your doctor to refer you to the Function and Mobility Clinic sooner. Visit this website if you would like to find a physiotherapist in your community:

 <http://publicregister.collegept.org/PublicServices/Start.aspx>

Keep track of how you are doing

For example, for the wall climbing exercises, reach as high as you can with your unaffected arm. Mark that point with a piece of tape. This will be the goal for your surgery-side arm.

Manage your pain

Feeling sore or some pain when exercising is normal. For example, you may feel like something is pulling inside. This is normal. You are feeling your scar tissue stretching.

If it is very painful or uncomfortable, take a break. But, don't stop exercising completely. Start slowly, and keep doing the exercises 1 step at a time. Be patient with yourself. You will slowly get stronger.

If you feel you cannot do your exercises because of pain, try to do the exercises about 20 to 30 minutes after taking pain medicine or a shower. Talk to your doctor, nurse, physical therapist or occupational therapist for ideas on how to manage your pain better.

When you exercise:

- Begin exercises slowly, without tiring or straining yourself. Do not force any movements. This includes activities you do at work, at home, or during sports and hobbies.
- Start with whatever you are able to do and slowly add more until you are able to repeat each exercise 5 to 10 times, 2 to 3 times a day. Hold each stretch for 3 to 5 deep breaths. Continue with these exercises every day until you can use your arm the way you did before.
- If you can, do the exercises in front of a mirror so you can make sure you keep good posture.

Start with exercises 1 to 6 on the first day after surgery:

If you have a drain, they are safe to do while the drain is still in.

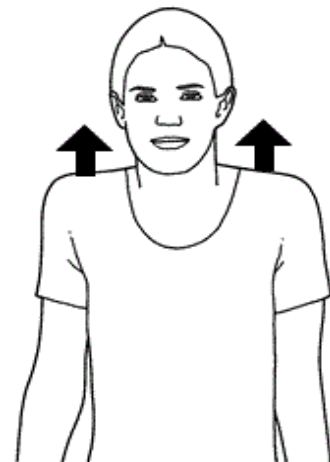
1. Making a fist - ball squeezes

- A. Open and close your fist 10 times every hour during the day.
- B. Try using a soft squeeze ball or sponge.



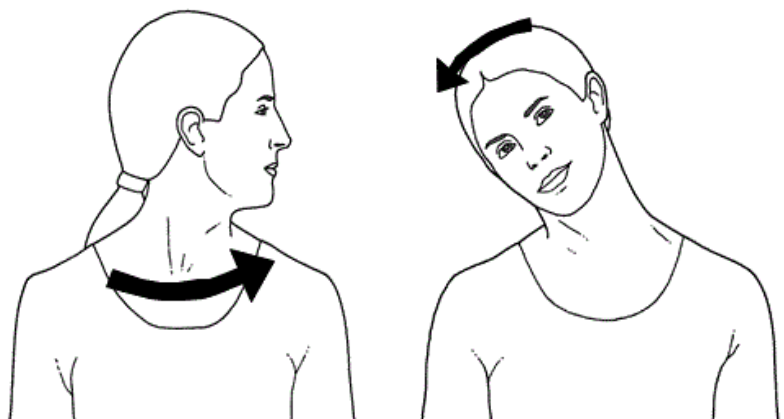
2. Shoulder shrugs

- A. Sit upright in a comfortable position.
- B. Raise your shoulders up towards your ears, bring your shoulder blades together at the back.
- C. Lower your shoulders, and relax.
- D. Repeat 5 to 10 times.



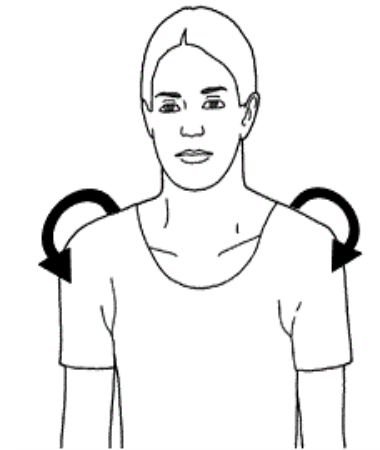
3. Head turning and tilting

- A. Stretch your neck as tall as possible, while keeping your chin in.
- B. Turn your head slowly, looking over each shoulder as far as you comfortably can.
- C. Tilt your head to one side and then the other, bringing your ear as close to your shoulder as you comfortably can.
- D. Repeat 5 to 10 times.



4. Shoulder circles

- A. Begin by making small, slow forward circles with your shoulder. Make sure you are moving your shoulder and not your elbow.
- B. Slowly increase the size of the circles as you are able.
- C. Reverse the direction of the circles and repeat steps A and B.



5. External arm rotation

- A. Sit or stand.
- B. Keep your upper arms and elbows close to your sides and elbows at right angles.
- C. Turn your forearms outwards while keeping your elbows at your side.
- D. Repeat 5 to 10 times.



6. Pendulum

- A. Bend over and use your unaffected hand to support yourself on a table.
- B. Swing your affected arm (like a pendulum) from left to right and back.
- C. Then, swing your whole arm forward and back.
- D. Repeat 5 to 10 times.

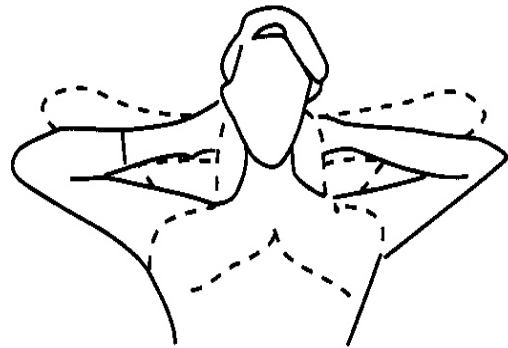


Start exercises 7 to 13 once your drain is removed. If you don't have a drain, start them 4 days after your surgery. These exercises are important to try to get back the full use of your shoulder.

7. Elbow push-back

This exercise helps increase the movement in the front of your chest and shoulders. You can do this exercise standing up against a wall or lying down on your back on a bed or the floor.

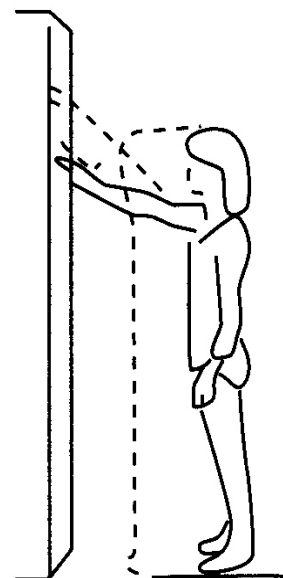
- A. Place your fingers behind your head or your upper neck.
- B. Spread your elbows out to the side as far as possible
- C. When you get to the point where you feel a good stretch (but not pain), take 3 to 5 deep breaths and hold the stretch. Keep your neck straight and relaxed as you do this.
- D. Repeat 5 to 10 times.



8. Shoulder flexion wall exercise

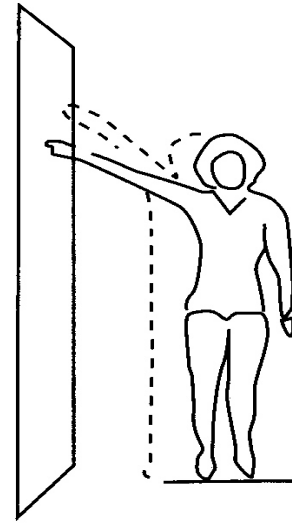
This exercise helps increase the forward movement of your shoulder. Try to reach a little higher each time. As you improve, move your feet and body closer to the wall.

- A. Stand facing a wall.
- B. Slide or walk your fingers up the wall as far as possible. When you get to the point where you feel a good stretch (but not pain), take 3 to 5 deep breaths and hold the stretch for 10 seconds.
- C. Return to the starting position by walking your fingers back down the wall.
- D. Repeat 5 to 10 times.



9. Shoulder side lifts wall exercise

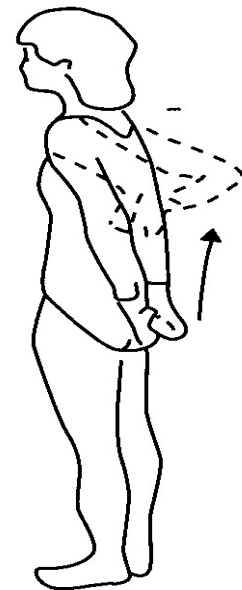
- A. Turn sideways with your affected side toward the wall.
- B. Slide or walk your fingers up the wall as far as possible. When you get to the point where you feel a good stretch (but not pain), take 3 to 5 deep breaths and hold the stretch for 10 seconds.
- C. Return to the starting position by walking your fingers back down the wall.
- D. Repeat 5 to 10 times.
- E. Try to reach a little higher each time. As you improve, move your feet and body closer to the wall.



10. Back climb exercise

This exercise helps you improve the movement behind your back. You need this for activities such as hooking your bra, buttoning up a blouse, or zipping up a dress. You can do this exercise sitting or standing.

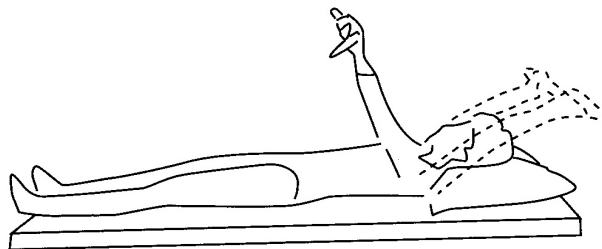
- A. Place your hands behind your back holding your surgery-side hand.
- B. Slowly slide your hands up the centre of your back as far as possible. When you get to the point where you feel a good stretch (but not pain), take 3 to 5 deep breaths and hold the stretch for 10 seconds.
- C. Lower your hands slowly.
- D. Repeat 5 to 10 times.



11. Forward lifting

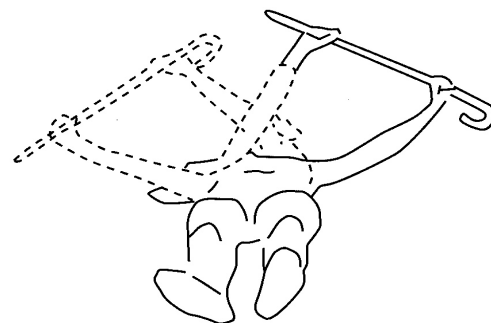
This exercise helps increase the forward movement of your shoulders.

- A. Lie on your back and hold a stick with both hands, palms down and arms shoulder width apart.
- B. Keeping your elbows straight, lift the stick over your head as far as you can. Use your unaffected arm to help lift the stick until you feel a stretch in your surgery-side arm.
- C. Hold the stretch for 3 to 5 deep breaths.
- D. Repeat 5 to 10 times.



12. Lifting to side

- A. Lie on your back and hold the stick with both hands, palms down and arms shoulder width apart.
- B. Lift the stick up in front of you.
- C. Move the stick toward the side that you had your surgery.
- D. When you begin to feel a stretch in your surgery-side arm, hold the stretch for 3 to 5 deep breaths.
- E. Repeat 5 to 10 times.



13. Chest wall stretch

- A. Stand facing a corner with your toes about 8 to 10 inches from the corner.
- B. Bend your elbows and put your forearms on the wall, one on each side of the corner. Your elbows should be as close to shoulder height as possible.
- C. Keep your arms and feet in place and move your chest toward the corner. You will feel a stretch across your chest and shoulders.
- D. Hold the stretch for 3 to 5 deep breaths.
- E. Repeat 5 to 10 times.



How can scar massage help?

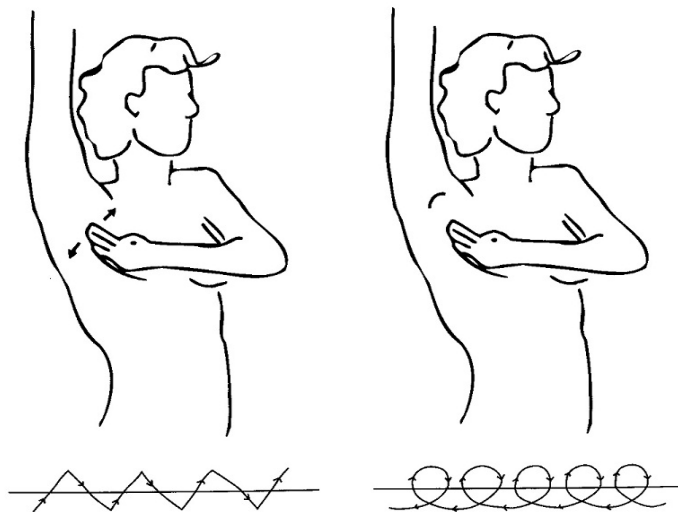
Scar massage is another way to help your shoulder get back its full range of motion and function.

Begin scar massage after your incisions (cuts) are completely healed and your drains are removed. This is usually about **3 weeks after surgery**.

You may find that your scar feels very sensitive, tight or itchy. Scar massage can help improve any sensitivity, tightness or itchiness you feel. It will help soften and loosen the scar and get the movement in your shoulder back more quickly.

To massage your scar:

1. Put a small amount of vitamin E lotion to your scar area. Before radiation, please talk to your radiation oncologist about using vitamin E.
2. Place 2 fingers or your thumb on the scar.
3. Press firmly but gently along your scar in an up and down zig-zag pattern. Move in 1 direction and then back in a circular motion.
4. Do this 2 to 3 times a day for about 10 minutes.



Do scar massage **before** you do the exercises. If you're not sure you are doing it correctly, ask your surgery nurse, physical or occupational therapist.



Remember: If you have any questions or concerns, you can talk to your physical or occupational therapist about:

- your exercises
- managing your scars
- how to manage your daily activities after surgery (for example, things like caring for yourself, daily chores, child care or returning to work)
- how to cope with pain and anxiety (for example, relaxation training)
- information and support for any sexuality or body image worries you may have

Other helpful resources



For a video of the exercises in this brochure, visit The Princess Margaret Patient and Family Library on the main floor. Ask for the **Your Functional Rehabilitation after Breast Surgery** exercise DVD (video).

Remember to ask your oncologist for a referral to The Princess Margaret **Function and Mobility Clinic** if you don't have your full range of motion back 8 weeks after your surgery.

You can also meet with a physiotherapist in your community. Visit this website to find one close to home:

 <http://publicregister.collegept.org/PublicServices/Start.aspx>

Princess Margaret Cancer Survivorship Program

Call ☎ 416 946 4501, extension 2363 for more information about:

- Function & Mobility Clinic
- Lymphedema Clinic
- Fatigue Clinic
- Physiatry Consults
- Wellness and Exercise Program
- Healthy Steps Exercise Class

Pick up your Patient Education Calendar from the Princess Margaret Patient and Family Library on the main floor. It has information about education sessions and exercise classes at Princess Margaret.

Call Psychosocial Oncology at ☎416 946 4525 for support in dealing with your emotional recovery after breast cancer.

Community resources

Canadian Cancer Society

☎Phone: 1 888 939 3333

💻Website: www.cancer.ca

Willow (telephone support)

☎Phone: 1 888 778 3100

💻Website: www.willow.org

Wellspring

☎Phone: 1 877 499 9904

💻Website: www.wellspring.ca

Gilda's Club (support group and other services)

☎Phone: 416 214 9898

💻Website: www.gildasclubtoronto.org

Rethink Breast Cancer

☎Phone: 1 866 738 4465

💻Website: <http://rethinkbreastcancer.com/>

Lymphedema Association of Ontario

☎Phone: 1 866 738 4465

💻Website: <https://lymphontario.wildapricot.org/>

Physiotherapy After Your Breast Surgery

This information is meant to help you in your recovery. We outline for you what to expect after surgery and give you tips on how to make a speedy recovery. Your Physiotherapist visits you soon after your surgery to get you started on the exercises you need to get back your strength and flexibility. Therapy helps to control your swelling and improves scar healing. You are given exercises to strengthen and stretch as well as improve your posture and overall fitness.

Remember...

Every person recovers differently.
Not everyone progresses at the same rate.

There are different types of breast surgery. Here is a short description of each one:

- **Mastectomy** – when the breast is removed either in whole or in part.
- **Breast reconstruction** – once a mastectomy has been done, the breast is re-created either with an implant (Breast Implant) or by making it from nearby muscle (TRAM Flap - Transverse Rectus Abdominus Myocutaneous flap).
- **Lumpectomy** – when only the lump is removed from the breast.
- **Lymph node biopsy** – when a small cut is made in the skin and a sample of tissue is taken from the lymph node. The sample is then sent to our laboratory to be examined. It is also called an axillary dissection. ‘Axillary’ is the medical term for armpit. ‘Dissection’ is another way of saying to look at something in detail.

The information in this booklet is for all who have had some type of breast surgery. We have included specific instructions for certain surgeries where needed.

We suggest you review the information and exercises. It would be good to **start practicing the exercises for at least 6 weeks before your surgery**. If you have any questions on how to do the exercises, talk to your doctor or a physiotherapist.

While in the hospital

You need to start doing your exercises the day after your surgery. You can expect to feel some soreness, as well as tightness or pulling of the skin, around your chest, armpits and stomach. You can expect to have a small amount of fluid leaking from your surgery site or incision.

You may find it is hard for you to lift your arm(s). This can be from pain, swelling and tightness of the surgery site. Doing your exercises helps with this. It is very important for you to do your exercises regularly. This helps prevent some of the problems described in this booklet. The Physiotherapist comes to see you soon after your surgery. Remember - the sooner you start on your therapy and exercises after your surgery, the faster you will recover.

Some people feel some numbness and tingling around their surgery site(s) or incision(s). It is possible that the numbness and tingling may never go away completely. The exercises we give you should help with this.

If you have had breast reconstruction involving the ‘TRAM Flap’, you may be told not to sit or stand up completely straight for the first day or two. After a few days, you need to start to slowly straighten up, otherwise it will be harder for you to improve your posture later. You may get some low back pain from being bent over, but this should go away in 3 – 7 days.

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Recovering At Home

A Quick Summary	
What to do	What NOT to do
<ul style="list-style-type: none"> Take sponge baths. Tub bath as long as you keep your incision(s) dry and can easily get in and out of the tub. Shower only after your incision(s) are fully healed and the stitches have been taken out. Take your pain medicine regularly and as needed. When sitting or lying down, rest your arm on pillows. 	<ul style="list-style-type: none"> Do not get your incision(s) wet until it is fully healed and the stitches have been taken out. Do not use ice or heat over your incisions. <p>For 8-12 weeks after the surgery:</p> <ul style="list-style-type: none"> Do not lift anything greater than 10 pounds. Do not do any heavy housework such as vacuuming.
For those who had the TRAM flap:	
To get up from the lying position, roll onto your side first and then sit up by pushing up with your elbow against the bed.	Do not try to pull yourself up from the lying position using your tummy muscles or arms.

When to call for help

Contact your surgeon **right away** if you have any of the following:

- Increased redness and increased heat around the incision site(s).
- Increased pain around the incision site(s).
- A lot of swelling around the incision site(s).
- Any bad smelling or unusual fluid coming from your incision(s).
- A fever - temperature over 38.5° C (101.3° F), using an ear or mouth thermometer.

These are signs of infection. You need to be treated as soon as possible. If you cannot get in touch with your surgeon, go to your nearest hospital emergency department.

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If you find you have any of the following after your surgery, we suggest you arrange to see a Physiotherapist within 2 to 6 weeks of going home:

- Stiffness in your arm(s).
- General swelling around your surgery site or in your arm(s) that does not go away.
- Tightness of your scars.
- Aching pain that is not getting better or going away.
- Leaking of urine when coughing or sneezing. (This is possible for those who have had the TRAM Flap).

What you can do to help with your recovery

Pain

After surgery you will be sore. Take your pain medicine as directed. Plan to do your exercises about 1 hour after taking pain medicine.

It may be hard for you to find a comfortable position to sleep. You will want to slouch and not want to sit up or stand up straight. This is especially true if you had breast reconstruction (TRAM Flap). After a few days, you should be more comfortable. It is important to try to sit and stand taller. It is normal to feel a mild stretch of the skin at the surgery site. You should not push yourself beyond this.

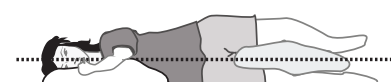
Lying on Your Back

Bolster under the knees so knees are bent and supported. A rolled comforter or sleeping bag can be used in place of a bolster.



Lying on Your Side

Both knees bent with a pillow between them. One soft pillow positioned to support the neck. Pillows in front of your chest to support your affected arm.



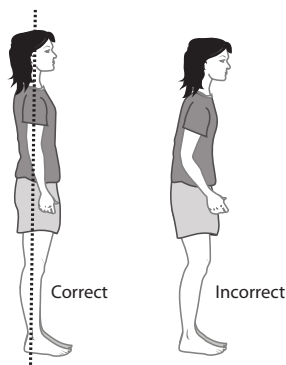
When sleeping or lying down, use pillows to help support yourself. You may find that lying on your back gives you a stretching feeling across your tummy. To help with this, use a pillow under your knees. Make sure that the pillow under your head is only under your head and not under your shoulders as well. The pillow keeps your head in line with the rest of your body. If you have the pillow under your shoulders as well, this is the same as slouching when sitting or standing. When lying on your side, you may find it helpful to have a pillow in front of your chest so you can rest your top arm on it. Another pillow between your knees may also help.

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Proper Sitting Posture

When sitting, sit in a good, firm and supportive chair. Chairs with armrests are best. Try to focus on standing and sitting tall with your shoulders back. Try not to slouch, roll your shoulders forwards or poke your chin outwards.



Proper Standing Posture

Swelling

It is normal to have some swelling around the surgical site, and in the arm, after your surgery. This should get less over time, but it can sometimes take up to 4 months to go away.

Sometimes a 'compression sleeve' is used to keep the swelling under control. A compression sleeve is like an elastic bandage. You pull it over your arm. It puts pressure on your arm from your wrist to your armpit. This helps move the lymph fluid up out of your arm. The sleeve works best when worn daily during waking hours. Those individuals who have had lymph nodes removed tend to have more swelling than those who did not. Talk to your doctor about prescribing a compression sleeve, especially if your swelling does not go away with the other ways described below. Compression sleeves are custom-made to fit you.

Swelling can cause pain and make it harder for you to use your arm. Here are other ways you can help keep the swelling down:

- When sitting or lying down, rest your arm on pillows. Keep your arm raised above your chest (or the level of your heart). This helps the swelling flow out of the arm.
- Make a fist. Open and close your hand 10 times, take a rest and repeat this cycle another two times. Do three sets of 10 every hour or so throughout the day. This helps move the fluids up and out of the arm.
- Keep active. **Do not be afraid to move.** Try to use your arms as you normally would use them.
- Do your exercises as instructed by your Physiotherapist.

Incision Care

Before you leave the hospital, your nurse will give you information on how to care for your incision(s) while they heal. Look for signs of infection. See your surgeon as soon as possible if any signs develop. (See "When to call for help")

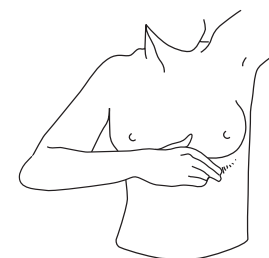
Scar

You will have a scar from the incisions. Depending on how the scar heals, it can become thick, limit how your skin stretches and moves, and may interfere with the muscles, nerves, and tendons underneath. Scars from this type of surgery can even limit how well you use the arm and shoulder on the surgery side. Sometimes scars become painful and sensitive to touch.

You can help your scar heal so that it does not limit your movement. You can begin massaging your scar when:

- ✓ Your stitches have been taken out,
- ✓ Your incision has fully healed, and
- ✓ Your surgeon gives you the go-ahead.

Scar massage helps increase the ability of the scarred skin to stretch and move when you do.



Stiff muscles in your arm and neck

After surgery, some muscles may become tight or stiff. The first step to getting your muscles moving is to stretch. So you do not hurt yourself, do your stretches slowly and steadily. Keep the stretch constant for the time needed. Do not bounce while in the stretch. This can hurt the muscles.

When you get to the point where you feel a mild stretch discomfort, hold the stretch at that point for 15 seconds. This helps the muscle to relax and lengthen. You should not feel any pain. If you do, you are stretching too far. Over time, you will be able to stretch further and further.

To help with your stretching, you may want to buy a set of exercise pulleys. They can be very useful in your recovery. These are inexpensive and they can be set-up easily at home. Talk to your Physiotherapist if you are interested in this.

Reduced arm function

Some people have found their arms do not feel strong and do not move as well as they should for up to 4 years after breast surgery. When muscles are weak and not used properly, it can reduce how well the arm moves.

Exercising every day both before and after surgery can help you return to your level of activity before surgery. Daily exercise helps improve lymph flow and keep arm swelling down. You should look at doing some type of ongoing exercise. Studies show there isn't one activity or sport that is better than another. What is important is keeping active. If you have an interest in an activity (such as Yoga) or sport, talk to your Physiotherapist. You will need a program or plan for how to gradually get into, or go back to, the activity or sport.

Weak Tummy Muscles

If you had the TRAM Flap surgery, you are likely to have weak tummy and low back muscles. So, it is important for you to do exercises to strengthen your tummy muscles, both before and after your surgery. (See the exercises checked off for you at the end of this booklet).

We know these are hard exercises to do. The best thing for you to do is to start doing your tummy muscle exercises every day for 6 weeks before your surgery. This helps you build up your strength and gives you the support you need after your surgery. Doing these exercises before your surgery makes them easier afterwards.

Also after TRAM Flap surgery, some people get problems with urine leaking. This happens when they cough or sneeze. These exercises also help strengthen those muscles that control urine flow (the muscles that hold your pee in).

Your Physiotherapist will talk to you about these exercises and make sure you are doing them correctly following your surgery. Since some of these exercises are hard to do correctly, you may find it helpful to see a Physiotherapist 6 weeks before your surgery so you can learn how to do them properly.

Returning to work

How soon you go back to work depends on what work you do and what type of surgery you had. Remember:

Every person recovers differently. Not everyone progresses at the same rate.

Your surgeon will let you know when it is safe for you to return to work. You may not be able to return to full hours and full duties right away. You may need a return-to-work plan that outlines a gradual increase in time and duties. Your surgeon and your Physiotherapist will help you draw up a plan for gradually returning to work (called a ‘gradual return-to-work plan’). Keep your employer up to date with how your recovery is going. Some employers have contact people who will need to be involved with your return-to-work plan.

Exercises for your recovery

You need to get moving soon after surgery. Your Physiotherapist will show you which exercises to do and when to do them. Exercises help you keep as much movement and strength in your arms, back and tummy muscles. Don’t forget - exercise also helps prevent the problems we have described in this booklet.

If you begin to hurt anywhere during your exercises, lie down and rest. If your arm begins to hurt, lie down and rest your arm up on pillows.

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Walking

Walking is a great way to get active after your surgery. It helps to keep your lungs and heart healthy. It is also a great way to relieve stress, control weight gain and combat fatigue.

Remember – it takes time to recover. Start slowly. Gradually increase your speed and the length of time you walk. If you have a history of heart or lung disease, check with your Family Doctor before starting a walking program.

A Sample Walking Program				
<div><ul style="list-style-type: none">• This program is a guide that will help you establish a walking program. You do not need to follow this program exactly. Start at a stage that feels right for you and progress at your own pace.• If you have been hospitalized for treatment of heart disease, this program is designed to follow the exercise program that was prescribed for you.• An advantage of walking is that you do not require any special equipment, other than a good pair of comfortable shoes.</div>				
Week	Warm-Up	Conditioning Phase	Cool-Down	
	Walk at an easy pace (Time in mins)	Walk at a brisk pace (Time in mins)	Walk at an easy pace (Time in mins)	Total Time
1	6	0	6	12
2	8	0	8	16
3	10	0	10	20
4	10	3	10	23
5	10	5	10	25
6	10	7	10	27
7	10	9	10	29
8	10	11	10	31
9	10	13	10	33

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Week	Warm-Up	Conditioning Phase	Cool-Down	
	Walk at an easy pace (Time in mins)	Walk at a brisk pace (Time in mins)	Walk at an easy pace (Time in mins)	Total Time
10	10	15	10	35
11	10	18	10	38
12	10	20	10	40
13	10	23	10	43
14	10	26	10	46
15	10	28	10	48
16	10	30	10	50

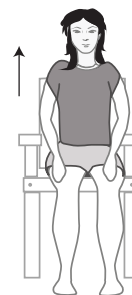
***During your walks, you should be able to carry on a conversation.
If you cannot, you should slow down.**

Other indicators that suggest you slow down are:

- If you have gone past your recommended target heart rate or rate of perceived exertion (RPE)
- you have shortness of breath
- you have discomfort in chest, arm, back, jaw, or unusual joint or muscle pain
- you have irregular heart beats
- you have dizziness or nausea

Go to the nearest Emergency Department or call 911 if your symptoms persist.

The following exercises can be started post-operatively once you feel comfortable.



Shoulder Shrugs

Raise shoulders up, then slowly press them down. Relax.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day.



Shoulder Blade Squeeze

Rotate shoulders back, then squeeze shoulder blades together.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day.

Forward Arm Reach



Place arm on table top. Slide hand and forearm forward until a stretch is felt. Hold position for 15 seconds. Relax body and repeat.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day.

Neck Range of Motion

Begin each neck exercise by tucking your chin towards your Adam's apple:

1.



1. Gently rotate your head to the right until a stretch is felt. Repeat on the left.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day.

2.



2. Gently tilt your head to your chest until a gentle stretch is felt on the back of your neck.

3.



3. Tuck your chin towards your Adam's apple and gently tilt your head towards the right until a gentle stretch is felt on the left side.

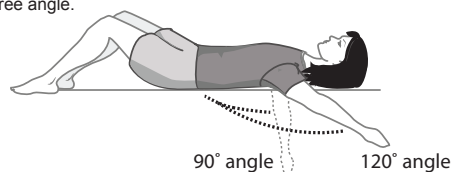
Repeat to the other side.

The following exercises can be started approximately 2 weeks post-surgery.

Pectoralis Stretch

Lie on your back at the edge of the bed. Bend your knees. Place your arm, with palm facing up, to the side of the bed at a 90 degree angle and progress to a 120 degree angle. Let it hang over the edge until a gentle stretch is felt.

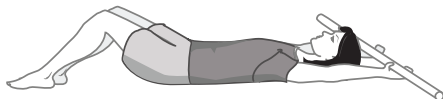
Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day



Overhead Flexion with Cane

Lie on your back with your knees bent. Hold a cane or stick in your hands. Keep elbows straight and raise cane overhead until a stretch is felt in your armpit and chest.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day



Trunk and Arm Stretch

Start on your hands and knees. Slowly lean back so you are sitting on the back of your heels. Keep your arms stretched out in front of you. Feel the stretch in your back and in the sides of your trunk.

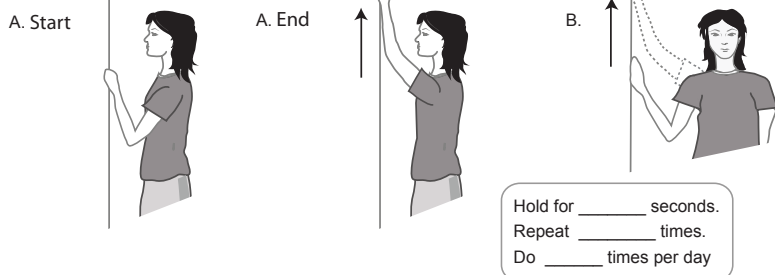
Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day



Wall Climbs

A. Stand facing a wall as close as possible. Bend your elbow and place the palm of your hand on the wall at shoulder height. Work your hand up the wall until your arm is stretched. Bring your hand back down to shoulder height in the same way.

B. Stand sideways on the wall with affected side close to the wall. Repeat the exercise climbing the wall with the affected arm only.



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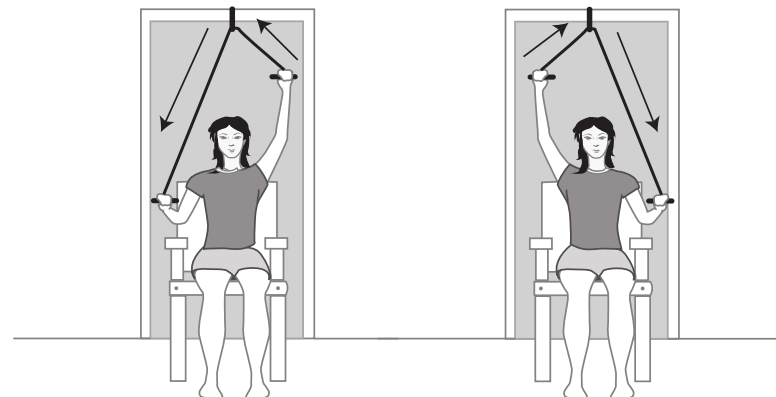
The exercises on this page may be started once you can sit comfortably in an upright position.

Overhead Pulleys

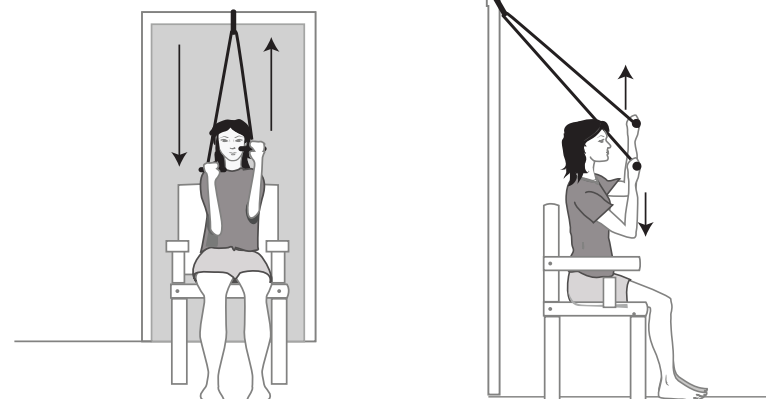
Abduction

Start Position

End Position



Forward Flexion



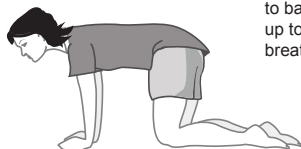
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The following exercises can be started approximately 6 weeks post-surgery.

✱ We recommend you progress through the exercises on this page in order, from 1 through 5.

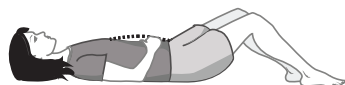
1. Lower Abdominal Exercises

In this 4-point kneeling position, make sure your back is flat. Relax your tummy muscles and breathe normally. Breathe in allowing your tummy to balloon, breathe out letting all of your air out. Draw your belly button up towards your spine, holding your tummy muscle tight. Resume breathing normally while maintaining your abdominal contraction.



Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

2. Lower Abdominal Exercises



Lie on your back, with knees bent. Relax your tummy muscles and breathe normally. Breathe in allowing your tummy to balloon, breathe out letting all of your air out. Draw your belly button to your spine and breathe normally holding your tummy muscle tight to your spine.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

4. Lower Abdominal Exercises



Lie on your back with your knees bent. Tighten your lower abdominals and slowly let your right leg fall out to the side without allowing any movement of your hips. Your hips must remain in contact with the bed (no rocking).

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

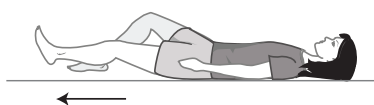
3. Lower Abdominal Exercises



While maintaining abdominal contractions described in previous exercise, and keeping right foot on bed, slowly straighten your left knee by sliding your left heel along the bed. Only straighten your leg to the point where you can maintain your abdominal contraction and NOT beyond. Slowly return to the starting position and repeat with the other leg.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

5. Lower Abdominal Exercises: Crook Lying



While maintaining abdominal contraction, and keeping right foot on bed, lift the left foot off the ground and slowly straighten your knee by gliding your foot in the air. Straighten your leg only to the point where you can maintain an abdominal contraction and NOT beyond that. Slowly return to the starting position and repeat with the left leg.

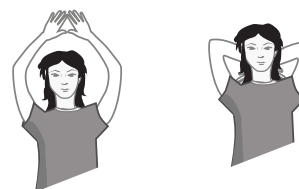
Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

Advanced Exercises

... the remaining exercises in this booklet can be started approximately 6 weeks post-surgery.

Bilateral Arm Raises (advanced)

Clasp both hands in front of you and straighten your elbows, raising your hands as high as possible above your head. Bring your hands down behind your head and stretch your elbows back. Relax both arms and rest. Repeat 5 times. Hold 15 seconds. Do not pull on your head and neck.



Standing Posture (advanced)

With your back against the wall, your feet shoulder width apart, knees slightly bent, try to flatten your lower back.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

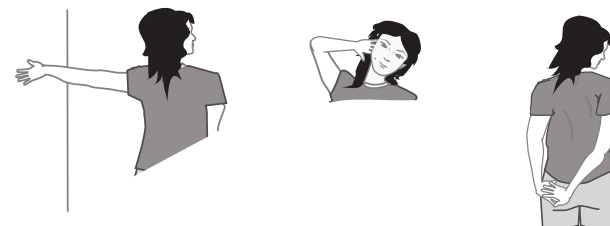


Back Scratching (advanced)

Holding the end of a towel in one hand, throw it over your shoulder. Place the other hand in the small of your back and grasp the other end of the towel. Move the towel up and down pulling your hands as far up and down your back as possible. Reverse hands and repeat the exercise 5 times and hold 15 seconds.



Neural Glides



Advanced Exercises

Standing Knee Flexion



Stand on your right leg. Hold onto a counter for support. Tighten your tummy. Bend your left leg up towards your buttock (keep your thigh in line with your leg). Keep your buttock tucked under.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

Repeat with Right leg.

Standing Hip Extension

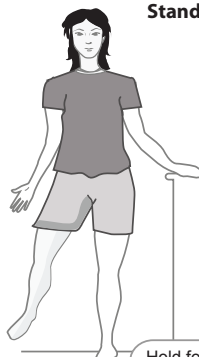


Stand on your right leg. Hold onto a counter for support. Tighten your tummy. Squeeze your buttocks and lift your Left leg backwards keeping your knee straight. Do not lean forward from your waist.

Hold for _____ seconds.
Repeat _____ times.
Add _____ lb. weight to ankle.

Repeat with Right leg.

Standing Hip Abduction

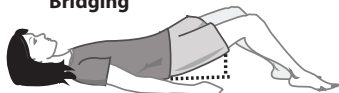


Stand on your left leg, keep your body upright and your tummy tucked in. Hold on to a stable object for support (e.g. counter top). Move your leg sideways. Keep your pelvis level, and knee caps and toes pointed forward. Do not lean sideways while lifting your leg. Return leg to center.

Hold for _____ seconds.
Repeat _____ times.
Add _____ lb. weight to ankle.

Repeat with Right leg.

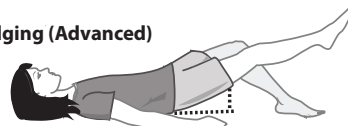
Bridging



Lie on your back with both knees bent and feet shoulder width apart. Tighten tummy muscles and lift your hips toward the ceiling. Keep pelvis level. Slowly lower hips.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

Bridging (Advanced)



Perform bridging exercise and then straighten one knee. Your knees should be level with each other. Slowly lower and then repeat with the other leg.

Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

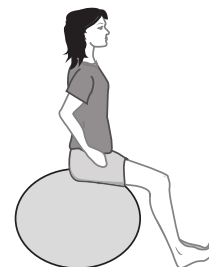
Advanced Exercises

Seated Ball Exercises

Start Position Sit on ball with feet flat on the floor. Tighten your core muscles.

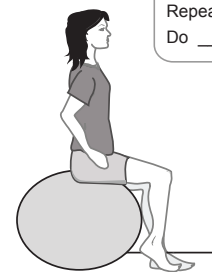


2. Lift toes of one foot off the floor while keeping core muscles tight. Hold 6 seconds and repeat 10 times.



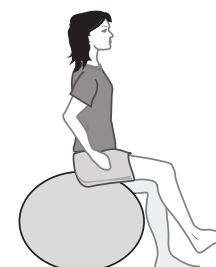
Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

1. Lift one heel off the floor while keeping core muscles tight.




Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

3. Lift one foot off the floor while keeping core muscles tight. Do not twist your body while sitting and lifting your leg.



Hold for _____ seconds.
Repeat _____ times.
Do _____ times per day

EXERCISE LOG																											
Exercises		Week of:							Week of:							Week of:											
		Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun					
1	Shoulder Shrugs																										
2	Shoulder Blade Squeezing																										
3	Forward Arm Reach																										
4	Standing Posture																										
5	Wall Climbs																										
6	Pectoralis Stretch																										
7	Overhead Flexion w/ Cane																										
8	Trunk and Arm Stretch																										
9	Neck Range of Motion																										
10	Overhead Pulleys																										
11	Lower Abdominal																										
12	Standing Knee Flexion																										
13	Standing Hip Extension																										
14	Standing Hip Abduction																										
15	Bridging																										
16	Bilateral Arm Raises																										
17	Back Scratching																										
18	Neural Glides																										
19	Seated Ball Exercises																										



To Contact the B.C. Nursing Hotline
Dial 811



How you want to be treated.