

**Lymphedema Working Group
2011-12**

Summary Report

April 12, 2012

PURPOSE AND BACKGROUND

In October 2011, the Ministry of Health convened a working group to review best practices, services, policies, procedures in the prevention and treatment of lymphedema in the province of Saskatchewan.

The Lymphedema Working Group was developed for the purposes of sharing information and providing advice to the Ministry of Health regarding services and supports to patients with lymphedema and individuals at risk of developing lymphedema.

The Group consisted of representatives from the Ministry of Health; Regional Health Authorities and various agencies that provide lymphedema services, supports, education and prevention; and patients who have recently engaged in the health system.

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A number of tasks were identified and completed by the Group to inform their purposes and advice provided to the Ministry of Health.

- An environmental scan of the current services and supports available in the province was completed. A total of 100 scans were sent out to health regions, the Cancer Agency, Physical Therapy Clinics, Registered Massage Therapists and Exercise Therapists. A summary of the environmental scan can be found in Appendix 1.
- Research on best practice diagnosis and treatment was gathered and reviewed by the members of the Group. Please see Appendix 2 for the bibliography of research gathered and examined.
- A presentation was provided to the group by a practicing certified lymphedema therapist in Saskatchewan. Information about what lymphedema is and how it develops, its interventions and treatments, challenges and best practices guidelines was provided.
- Gaps and needs in prevention, assessment and diagnosis, education, training, programs, services, and policies that impact patients were identified.
- An array of possible solutions to issues related to policies, programming, prevention, assessment and diagnosis, education and implementation of lymphedema treatment throughout the province was developed.

Lymphedema and Its Treatment

Lymphedema is a chronic condition of localized fluid retention and tissue swelling caused by a compromised lymphatic system. Lymphedema is the result of accumulation of fluid and other elements (e.g. protein) in the tissue spaces due to an imbalance between interstitial fluid production and transport. This can develop when lymphatic vessels are missing or impaired, or when lymph vessels are damaged or removed. The condition can be characterized as primary or secondary:

- Primary - present at birth, develop at the onset of puberty, or in adulthood, from unknown causes or associated with vascular conditions such as Hemangioma, Lymphangioma, Port Wine Stain, and Klippel Trenaury Syndrome.
- Secondary - is acquired due to an injured lymphatic system. The most common causes being cancer surgery, radiation therapy, trauma, inflammation and infection.

Lymphedema may result in significant physical illness and psychological impact resulting in a compromised ability to perform routine activities of daily living and vocation activities. Increased limb size can interfere with mobility and affect body image. Pain and discomfort are frequent symptoms and patients may experience acute infection and inflammation of tissues and skin that result in frequent hospitalization and long-term dependence on antibiotics. Lymphedema is not curable at present. Without early diagnosis, treatment, and on going management it is a progressive and irreversible condition.

Complex Decongestive Therapy (CDT) is the recommended best practice for the treatment of lymphedema. CDT consists of compression bandaging and garments, exercise, Manual Lymphatic Drainage (MLD), and skin care. Additional treatments include elevation and compression pumps for early mild lymphedema. All treatments are for symptomatic benefit, while also minimizing the development of further complications.

CDT and MLD are time intensive, direct treatments for lymphedema. The ideal treatment plan and the duration, length and frequency of treatments depend on the stage of lymphedema and are determined by a certified clinician.

Lymphedema Treatments in Saskatchewan

Seven Therapies Departments in health regions in Saskatchewan reported that they may provide primary and secondary lymphedema education, prevention and management strategies including compression garments along with range of motion, strengthening, soft tissue mobilization, manual physical therapy and graduated return to work assistance and monitoring. CDT is provided in Regina Qu'Appelle Health Region (RQHR) only and MLD or CDT is not a Saskatchewan Health Card benefit.

Training in CDT and MLD is not provided as part of any professional degree however, chiropractors, nurses, physicians, physical therapists and massage therapists may obtain certification following their professional training. An environmental scan completed by the Working Group identified four private therapists and one part time publicly funded therapist providing MLD and CDT in the province. The publicly funded position in RQHR only provides CDT to patients presenting secondary lymphedema following breast cancer surgery. RQHR refers patients with lower extremity lymphedema to private therapists for compression bandaging and MLD. Private therapy ranges from \$60-\$80 per visit.

The Saskatchewan Aids to Independent Living (SAIL) Compression Garment Program covers the cost of compression garments (including compression wrap) for clients who have serious conditions (including lymphedema) that require moderate to high pressure (20 mmHg or higher) that cannot be managed by other means such as elevation or medication and would become more severe without compression. Garments must be requisitioned by an occupational or physical therapist, or an enterostomal therapy, diabetes or wound care nurse. Garments are purchased and shipped to clients and replaced every six months or more frequently if required.

The SAIL Special Needs Equipment Program provides the free loan of lymphedema control units (three chamber pressure pumps) and the related pressure sleeves when requisitioned by a physiatrist, occupational therapist or physical therapist.

A grant option is available to clients with a diagnosis of primary lymphedema for the purchase of a multi-chambered (six or more) lymphedema pump. SAIL will reimburse the client for 2/3 of the actual cost of the pump, sleeves and accessories to a maximum of \$4000 once every five years.

ANALYSIS AND FINDINGS

Gaps and Issues

Utilizing information obtained from the environmental scan and weighing it with current best practice guidelines, the Group identified an array of gaps and issues across the continuum of lymphedema care in Saskatchewan. Gaps and issues were prioritized by highest need in each of the areas of: prevention and education; assessment/diagnosis; and treatment and intervention. The complete listing of gaps and issues can be found in Appendix 3.

Priority Prevention and Education Gaps:

1. Standardized information provided throughout the province pre- and post operatively on secondary lymphedema signs/symptoms and prevention strategies.
2. Health professionals across the continuum of care, including surgical best practices, require knowledge in primary and secondary lymphedema prevention, assessment/diagnosis and treatment.

Priority Assessment and Diagnosis Gaps:

1. Limited publicly funded diagnostic services and providers available.
2. Consistent or regular follow-up and assessment.

Priority Treatment and Intervention Gaps:

1. Targeted funding in all health regions to support treatment and intervention of primary and secondary lymphedema across the continuum of care.
2. Certification standards for service providers treating primary and secondary lymphedema.
3. Comprehensive multidisciplinary teams providing early diagnosis and assessment for primary and secondary lymphedema targeting appropriate levels of service to tertiary and regional hospitals.
4. Lymph pump policies and processes to meet the needs of all lymphedema patients.
5. Compression garment policies and processes to meet the needs of all lymphedema patients.
6. Skin and nail care clinics to meet the needs of lymphedema patients in the health regions.

SOLUTIONS AND ADVICE

The Lymphedema Working Group provides the following advice to the Ministry of Health to address the group's prioritized gaps in primary and secondary lymphedema services in the province of Saskatchewan. Solutions appear in random order as the working group did not prioritize these solutions.

Assessment and Diagnosis:

- a) Establish a virtual multidisciplinary diagnostic lymphedema team* to provide assessment and diagnosis to patients across the province.
- b) Provide out of province travel and accommodation for patients seeking assessment and treatment through an out of province referral.

Prevention and Education:

- a) Establish patient navigators to review information at regular intervals, advocate, and support patients across the continuum of care.
- b) Develop a provincial patient education package on signs/symptoms and preventions strategies for secondary lymphedema. Provide this package on line as well as at discharge from hospital.
- c) Expand the Regina Qu'Appelle Health Region's Breast Cancer class to all health regions. Pre-operative and primary lymphedema curricula should be added and enhanced.
- d) Explore the potential of HealthLine support for lymphedema.
- e) Develop education materials for health professionals across the continuum of care to increase knowledge and awareness of lymphedema and its prevention, treatment, and management.

Treatment and Intervention:

- a) Target funding in all health regions to support the development of specialized and regional lymphedema treatment and intervention programs.
- b) Establish comprehensive multidisciplinary teams for the provision of early diagnosis and assessment of primary and secondary lymphedema and treatment and intervention teams providing specialized and regional services across the province.
- c) Develop a lymphedema clinical pathway with primary and secondary lymphedema entry points for diagnosis and treatment.
- d) Develop a training fund for the education of health professionals to provide specialized and regional lymphedema assessment, prevention and treatment.
- e) Establish partnerships among health regions and charities for the provision of education and training opportunities and other one-time projects.
- f) Educate patients, service providers and referral sources on the certification standards recommended for the provision of lymphedema treatment.

* A group of professionals located across the province form a team specialized in the care of Lymphedema.

- g) Review and revise the lymph pump and compression garment policies and processes within the Saskatchewan Aids for Independent Living Program to meet the needs of all lymphedema patients.
- h) Enhance skin and nail care clinics across the province to include a multidisciplinary approach to wound care in lymphedema patients.

Appendix 1

Summary of the Environmental Scan

A total of 100 scans were sent out to health regions, the Cancer Agency, Physical Therapy Clinics, Registered Massage Therapists and Exercise Therapists. Seven health regions, the Saskatchewan Cancer Agency, three private massage therapists and five private Physical Therapy clinics responded to the scan.

Prevention and Education

All respondents reported that they provide prevention and education in the area of lymphedema prevention and treatment. Individual and small group sessions are provided at a cost to the patient ranging from no cost through a health region service to \$75 per session from a private clinic or therapist. A variety of prevention and education materials were reported to be used by therapist.

Treatment and Intervention

All health regions provide physical therapy and/or occupational therapy follow up to surgeries performed in Saskatchewan through the Surgical Initiative. Range of Motion, strengthening, soft tissue mobilization, manual physical therapy and graduated return to work assistance and monitoring may be provided through the therapies departments in each health region. Education, prevention and management strategies are also provided.

Manual Lymph Drainage (MLD) is typically referred out of the health region setting to a private therapist in the community. Therapy charges range from \$45 – \$65 per session. MLD is being completed by therapists reporting specialized training in the field. Many therapist reported that they had the training however, were not providing and had not provided treatment for patients. Four therapists reported providing MLD.

Exercise, range of motion, and strengthening are also provided by private therapist in the province at a range of \$10 – 65 per session.

The Ministry of Health's Saskatchewan Aids to Independent Living (SAIL) Compression Garment Program covers the cost of compression garments (including compression wrap) for clients who have serious conditions (including lymphedema) that require moderate to high pressure (20 mmHg or higher) that cannot be managed by other means such as elevation or medication and would become more severe without compression. Garments must be requisitioned by an occupational or physical therapist, or an enterostomal therapy, diabetes or wound care nurse. Garments are purchased and shipped to clients and replaced every six months or more frequently if required.

The SAIL Special Needs Equipment Program provides the free loan of lymphedema control units (three chamber pressure pumps) and the related pressure sleeves when requisitioned by a physiatrist, occupational therapist or physical therapist.

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the client for 2/3 of the actual cost of the pump, sleeves and accessories to a maximum of \$4000 once every five years.

Assessment and Diagnosis

Seven health regions reported the provision of an assessment for secondary lymphedema through their physical therapy clinics. Typically assessments are for the prescription of compression garments and physical therapy. Specialized assessment was reported by one health region for primary and secondary lymphedema with a referral to a private clinic for lower extremity lymphedema compression bandaging and MLD.

Appendix 2 ***References***

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Appendix 3 ***Comprehensive List of Identified Gaps and Issues***

Assessment and Diagnosis:

- Limited publicly funded diagnostic services/providers.
- Limited to no monitor/follow-up to watch for/prevent conditions and complications
- Consistent and regular follow up and assessment.
- Limited diagnostic of primary lymphedema in the province and Canada (testing, etc)
- Limited service providers and knowledge in lymphedema and its treatment and management
 - physicians
 - home care nurses
 - patients
 - physical therapist
 - inpatient clinical staff
- Limited psychosocial assessment at diagnosis.

Prevention and Education:

- Lack of lymphedema knowledge within the health care system.
- Financial barriers exist for patients to access private services
- Lack of continuity
- Standardized information not available to patients or from a number of sources
- Lack of education for family members and insurance companies
- Breast cancer class only offered in Regina
- Education before surgery and pre-op measurements not done
- Lack of follow up for both primary and secondary lymphedema
- Educational material only available in English – missing cultural aspect
- Lack of consistency throughout the province
- Surgeons should perhaps look at prevention by sentinel node dissection if possible rather than complete lymph removal
- Surgeons need to notify patients before surgery of physical ramifications, nerve damage, and lymphedema.
- Water therapy

Treatment and Intervention:

- Currently no certification standards for providers
- Financial implications to patients may be high
- Access in rural settings is limited
- Smooth referral from acute care to rehab is not in place
- Physician education/referral is needed
- Treatment appropriateness and planning needs to be enhanced
- Lower extremity follow up is limited and inconsistent
- Inappropriate identification of therapists with experience/certification in treatment
- Limited training in nursing in home care wound care
- No psychosocial support
- Access in rural areas not there

- Family education needed
- Point of contact person, a navigator is needed
- Learning processes for referral
- Multidisciplinary care approach
- Funding for providers to be trained in Complex Decongestive Therapy (CDT)
- Physical Therapists have limited treatment training in the graduate work
 - can identify it but the clinical practice is limited
 - support for return to work – employers need education around job duty modification which may be needed.
- Child care needed during treatment
- Bandaging support has been denied
- Ordering garment process is a barrier
- SAIL process/paperwork onerous
- 1-3 chamber pumps are contraindicated for long term use
- Limited availability of multi-chamber drainage pumps in the province
- Pump grant should be based on need/stage not diagnosis
- Diagnosis is an issue
- Private CDT therapist should be able to fit compression garments for SAIL
- Out of Province treatment or assessment does not cover travel
- Multi-chamber pumps are not widely available in the province
- Skin care is not covered and foot and hand clinics are required
- Night time garments are not covered and inelastic adjustable garments are not covered.