



CENTRE FOR FAMILY MEDICINE FHT
PRIMARY CARE MOBILITY CLINIC

Caring for Individuals with Spinal Cord Injuries & Physical Disabilities

JAMES MILLIGAN

PATRICIA FROESE

JOSEPH LEE

JORDACHE MCLEOD

LINDSAY DONALDSON

ALLISON HARRISON

MATT SMITH

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INTRODUCTION

This manual was created to disseminate the resources and lessons learned by the Centre for Family Medicine (CFFM FHT) Primary Care Mobility Clinic. Established in 2010, the CFFM FHT Primary Care Mobility Clinic was established with the support of the Ontario Neurotrauma Foundation (ONF) and the Schlegel-UW Research Institute for Aging (RIA) to address mobility issues through evidence-informed research, service provisions, and education. The Primary Care Mobility Clinic focuses on primary care for persons with spinal cord injury (SCI) and other physical disabilities by understanding the many barriers affecting these individuals and the development of solutions.

The needs of these patients are complex, often requiring a multitude of care providers. For this reason, the audience for this manual is diverse. This manual is meant to serve as a resource to primary care providers, interdisciplinary health professionals, advocacy groups, policy makers, researchers, and individuals with physical disabilities and their support givers.

This manual was developed using an Ontario lens recognizing primary care is heterogeneous. Many of the challenges are similar across Canada (and globally) and therefore we believe this information will translate beyond Ontario; the main limitations would include resources and systems within various geographic locations. We initially developed the tools and resources to the SCI population but soon realized they were generalizable to other physical disabilities seen in primary care such as multiple sclerosis, stroke, muscular dystrophy and other health conditions that result in severe physical disabilities.

Through the funding and support of the Ontario Ministry of Health and Long-Term Care, we embarked on developing a virtual care solution and training/support strategy for the Mobility Clinic. This was developed from lessons learned during the COVID-19 pandemic, and our previous experiences in utilizing virtual care to help facilitate access for patients with physical disabilities [Examining the impact of Virtual Integration Platform for individuals with Spinal Cord Injury (VIP4SCI) 2018 and Enhancing Spinal Cord Injury Primary Care through E- Consultation: A Pilot Study. Fortune J Health Sci. 2018]

ACKNOWLEDGEMENTS

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INTRODUCTION TO SPINAL CORD INJURIES

The spinal cord consists of the nerve fibres/fibers and tissues that are enclosed in the spine. It connects all parts of the body to the brain, with which it forms the central nervous system.

TYPES OF INJURIES

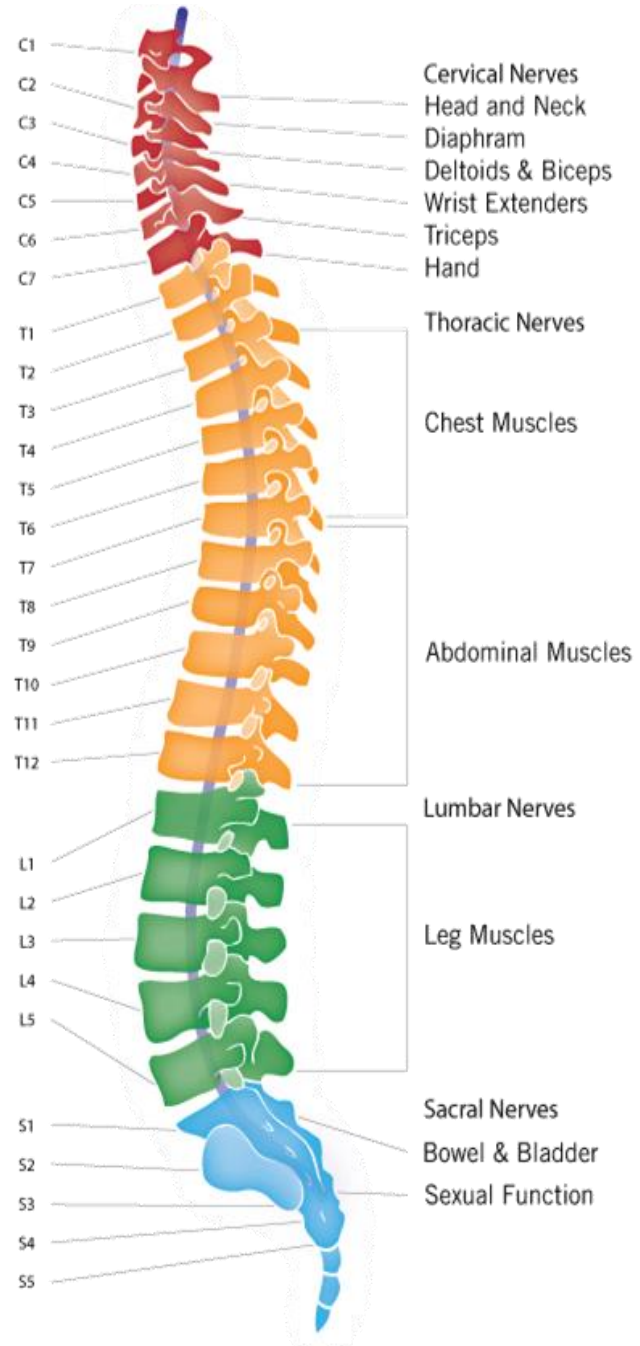
TRAUMATIC SPINAL CORD INJURY

A spinal cord injury resulting from an external force, such as falls, car accidents, or sports injuries.²

NON-TRAUMATIC SPINAL CORD INJURY

A spinal cord injury that is not caused by an external force, such as tumors, infections, neurodegenerative conditions such as cervical myelopathy, surgical complications, or spina bifida.²

FIGURE 1. Spinal Cord



(Rick Hansen Institute. 2016) [cited September 20 2016].
Available from: <http://www.rickhanseninstitute.org/resource/sci/what-is-sci>

DEFINITIONS

Spinal Cord Injury	The term 'spinal cord injury' refers to damage to the spinal cord resulting from trauma (e.g., a car crash) or from disease or degeneration (e.g., cancer). ³
Spinal Cord Injury Disease	Certain conditions can also damage the spinal cord. These conditions, diseases and disorders are known as spinal cord disorders or spinal cord diseases (SCI/D) or non-traumatic SCI (e.g., multiple sclerosis, amyotrophic lateral sclerosis, spina bifida, spinal tumours, vascular causes, spinal stenosis). ⁴⁻⁶
Paraplegia	Paraplegia is a term to describe an individual who has lost feeling and/or the ability to move in the lower parts of their body, including their chest, stomach, hips, or legs. Generally, their level of injury is somewhere between the second thoracic vertebrae and the fifth sacral vertebrae. ⁷
Tetraplegia	Tetraplegia is used to describe an individual with a SCI from the first cervical vertebrae (C1) to the first thoracic vertebrae (T1). Generally, they experience some loss of feeling or movement below the head. ⁷
Incomplete spinal Cord Injury	Still some feeling or movement below the level of injury. ⁷
Complete Spinal Cord Injury	There is no feeling or movement below the level of injury. ⁷
Cervical Myelopathy	Degenerative cervical myelopathy (DCM) includes age-related degenerative pathologies of the cervical spine that lead to myelopathy (neurological deficit/injury to spinal cord) from compression of the spinal cord. The degenerative conditions associated with DCM include cervical spondylosis (osteoarthritic degeneration) and ligamentous changes (ossification of the posterior longitudinal ligament (OPLL) or ligamentum flavum hypertrophy). ⁸⁻¹⁰

RANGES OF MOBILITY

INTERNATIONAL STANDARDS FOR NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY (ISNCSCI)⁷

ASIA GRADE	LEVEL OF INJURY
A	Complete; No sensory or motor function is preserved in the sacral segments S4-S5.
B	Sensory incomplete; Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5 (light touch, pin prick at S4-S5 or deep anal pressure), AND no motor function is preserved more than three levels below the motor level on either side of the body.
C	Motor incomplete; Motor function is preserved below the neurological level and more than half of key muscle functions below the single neurological level of injury (NLI) have a muscle grade less than 3.

D	Motor incomplete; Motor function is preserved below the neurological level and at least half of key muscle functions below the NLI have a muscle grade of 3 or greater.
E	Normal; If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without an initial SCI does not receive an AIS grade.

LEVEL OF INJURY AND RELATED FUNCTION¹¹

LEVEL OF INJURY	POSSIBLE IMPAIRMENT	REHABILITATION POTENTIAL
C2 - C3	Usually fatal as a result of inability to breathe	Totally dependent for all care
C4	Quadriplegia and breathing difficulty	Dependent for all care; usually needs a ventilator
C-5	Quadriplegia with some shoulder and elbow function	May be able to feed self-using assistive devices; usually can breathe without a ventilator, but may need other types of respiratory support
C6	Quadriplegia with shoulder, elbow, and some wrist function	May be able to propel a wheelchair inside on smooth surfaces; may be able to help feed, groom, and dress self; dependent on others for transfers
C7	Quadriplegia with shoulder, elbow, wrist, and some hand function	May be able to propel a wheelchair outside, transfer self, and drive a car with special adaptations; may be able to help with bowel and bladder programs
C8	Quadriplegia with normal arm function; hand weakness	May be able to propel a wheelchair outside, transfer self, and drive a car with special adaptations; may be able to help with bowel and bladder programs
T1 - T6	Paraplegia with loss of function below mid-chest; full control of arms	Independent with self-care and in wheelchair; able to be employed full time
T6 - T12	Paraplegia with loss of function below the waist; good control of torso	Good sitting balance; greater ability for operation of a wheelchair and athletic activities
L1 - L5	Paraplegia with varying degrees of muscle involvement in the legs	May be able to walk short distances with braces and assistive devices

EPIDEMIOLOGY OF SPINAL CORD INJURIES & PHYSICAL DISABILITIES

Disability has been difficult to define as it can affect individuals in very different ways. The most recognized definition often comes from the World Health Organization (WHO), *Disabilities* is an umbrella term, covering impairments, activity limitations, and participation restrictions. An *impairment* is a problem in body function or structure; an *activity limitation* is a difficulty encountered by an individual in

executing a task or action; while a *participation restriction* is a problem experienced by an individual in involvement in life situations.¹² According to the WHO there is an estimated 16% of the global population currently with a significant disability. In Canada, there was estimated to be 14.3 % of population that had a disability in 2006.¹³ There are significant inequities encountered by persons with disabilities in society but also healthcare, and as a result individuals face access to care, greater onset of chronic conditions (diabetes, heart disease, stroke), and on average live 20 years less than the general population.

It is estimated that the incidence of spinal cord injuries in Canada is 3-5 per 100,000 persons. Of spinal cord injuries, approximately 40% of those injuries are traumatic, often resulting from motor vehicle accidents or falls, and 60% are non-traumatic caused by conditions such as tumors or neurodegenerative disorders.¹⁴ With the ageing population there is an increased incidence of SCI in the older population due to chronic causes of spinal cord injury.

The most common form of spinal cord dysfunction in adults over the age of 55 is degenerative cervical myelopathy (DCM).^{15,16} DCM is a degenerative condition that results in motor and sensory decline due to compression of the spinal cord.^{9,15,17} This is an important condition for primary care providers as literature indicates that the most common initial point of contact for those developing DCM is the primary care provider,¹⁸ and family physicians and health care professionals will be confronted with an increase in the number of patients presenting with a wide spectrum of symptoms relating to various stages of DCM.¹⁹ The range of symptoms from DCM are broad, ranging from mild dysfunction, such as numbness or dexterity problems, to severe, such as quadraparesis and incontinence.^{9,15,19,20} However, due to the variability of clinical presentation, DCM can be very difficult to diagnose, with delay times of up to two years before a diagnosis is made. Behrbalk *et al.* (2013) found that delayed diagnosis was due to lack of knowledge within the primary care setting.²⁰ There exists an important opportunity to affect the outcomes of this potentially devastating condition.

TIMELINE OF CARE CONTINUUM

From acute care to rehab to primary care, this section outlines a common journey for some acquired physical disabilities (e.g. stroke, SCI, brain injury) from hospitalization to transition back to their community. For other disabilities, there may not be the same course (e.g. cerebral palsy, multiple sclerosis, amyotrophic lateral sclerosis).



A PATIENT'S EXPERIENCE...

Colin Smith, a 43 year old man, suffered a spinal cord injury following a motor vehicle accident 2 years ago. After paramedics stabilized Colin, he was taken to a hospital capable of providing appropriate comprehensive care to spinal cord injured patients. A MRI revealed spinal cord injury (or maybe use fracture/dislocations) at the level of C6. After surgery to decompress and stabilize the spine, Colin was transferred back to the unit. Colin had some sensation in his shoulders, elbows, and wrists, and had limited motor capacity. While in hospital, Colin experienced many new symptoms such as periods of muscle spasms, pain, profuse sweating, and dizziness. He received education about his injury, and saw many care providers. After 3 months of wearing a brace, Colin's condition was stable, he was able to sit in his wheelchair for approximately 2 hours, and he felt ready to start his rehabilitation. Colin was then transferred to a rehabilitation centre.

During his 14 week stay at the rehabilitation centre, Colin was taught skills to assist him in moving around in his wheelchair, bathing, dressing, skin care, bowel and bladder care, and transferring. His healthcare team included many individuals (physiatrist, nurses, physiotherapists, occupational therapists, social worker, and recreational therapist) and he was contacted by a representative from the local spinal cord injury advocate group (SCI Ontario). At the time of his discharge, Colin was able to get around in his wheelchair, required assistance with transfers, bathing, dressing, and bowel care, had an indwelling catheter, and alterations to his home were about to begin to ease with his transition.

Two months after being discharged from the rehabilitation hospital, Colin is struggling with his transition. The alterations to his home that were scheduled have yet to start and, as a result, he has been forced to have his bed in the living room of his home. He has been unable to return to his job as a mechanic, has difficulty getting out of the house, and is depressed. His wife, Maria, had to quit her job to be Colin's primary care provider, subsequently causing them to go into debt. Maria is beginning to experience burn out, and it is taking a toll on their marriage.

ACUTE CARE

Acute care refers to emergent care delivered following an acute event (e.g. stroke, spinal cord injury) or the need for urgent care due to complication of a condition (e.g. MS exacerbation, urinary tract infection).

Depending on the nature of the injury and severity, the length of hospitalization varies.

REHABILITATION CARE²¹

Once medically stable, patients may go to a rehabilitation program in a hospital setting. The structure varies between hospitals but in general, rehabilitation consists of an inpatient and outpatient program.

INPATIENT REHABILITATION PROGRAMS

Patients are transferred to these programs once their health is stable and they are physically able to participate. These programs focus care on:

- Activities of daily living such as getting around/ambulating, bathing, dressing, and directing own care
- Bowel and bladder management
- Skin care

Patients will work with the following providers for care:

- Physiotherapy and occupational therapy
- Nursing
- Pharmacy
- Dietitian
- Social work, psychology
- Therapeutic recreationist
- SCI regional service coordinator and a peer support worker from SCI Ontario

OUTPATIENT REHABILITATION PROGRAMS

Once discharged from an inpatient rehabilitation program, patients may require further services in an outpatient setting.

DISCHARGE PLANNING

Discharge planning is multi-staged and often requires a gradual re-introduction back into the community. Discharge back into the community does not mean that rehabilitation has ended; only that rehabilitation has become home-based and functional.

CHALLENGES WITH DISCHARGES

- Inadequate resources in the community
- Living situation not finalized such as home renovations not complete or long waiting list for housing
- Orders written by doctors that accompany patients to rehab often don't reach the primary care provider post-rehab

CARING FOR PATIENTS WITH SPINAL CORD INJURY AND PHYSICAL DISABILITIES: THE ROLE OF THE PRIMARY CARE PROVIDER

Individuals with physical disabilities often have complex care needs and are at higher risk for a number of health complications. Primary care providers have an integral role in the care for patients with physical disabilities. Primary care providers are uniquely positioned to provide comprehensive care that is tailored to the individual; they often have a pre-existing clinical relationship with the patient, have a broad scope of practice that is well-suited to address the biopsychosocial needs of the patient, and may also have timely access to allied health professionals.²²

Many barriers – physical, knowledge, attitudinal and systemic – make providing and accessing high-quality primary care that addresses the specific needs of patients with physical disabilities, challenging.²² As such, many patients continue to have unmet care needs in physical, psychological, sexual and reproductive health, as well as lifestyle and community functioning. Because accessing primary care is difficult, patients often resort to emergency department visits. Yet, a study by Guilcher et. al (2010) found that 50% of the emergency department visits by SCI patients were considered low acuity and could be managed by a primary care provider.²² Through better knowledge dissemination and training, primary care providers can be better equipped to manage these challenges and provide care for the complex needs of this population.

Common topics for primary care providers to address with an individual with spinal cord injury (see Case Based Learning Modules on our [website](#) for more information)

Preventative (immunizations, cancer screening)	Pressure injuries
Autonomic dysreflexia	Bone health
Neurogenic bladder	Sexual health
Neurogenic bowel	Respiratory health
Pain	Spasticity

The following sections will outline common barriers to care and provide suggestions for overcoming these challenges.

COMMON CHALLENGES IN TREATING PATIENTS WITH PHYSICAL DISABILITIES IN THE PRIMARY CARE SETTING

Physical, knowledge, attitudinal and/or systemic barriers often limit ability to provide and access care for patients.

PHYSICAL BARRIERS

Patients with mobility impairments often face challenges in visiting and being examined by their primary care provider, with some common examples being:

- Difficulty securing transportation to and from appointments
- Office inaccessibility:
 - Lack of wheelchair ramps
 - Small office space that makes maneuvering or transferring to an examination table challenging
 - Lack of appropriate equipment, such as height-adjusted examination tables and grab bars^{24,25}
 - Lack of staffing, training, or familiarity with specialised equipment, when it is available
 - Scheduling issues (length and time of day of appointment, flexibility)

These barriers compromise quality of care and can potentially lead to adverse outcomes, such as when patient weight is incorrectly estimated in drug dose calculations in the absence of an accessible scale, or when early signs of secondary complications are missed because a proper exam is not possible.²²

Additionally, primary care providers may not be aware of potential accessibility challenges among specialists and community services when referring or ordering tests, which can lead to delay in care.

KNOWLEDGE BARRIERS

Many primary care physicians are not knowledgeable about physical disabilities and the secondary complications and potential effects on all body systems and therefore may be reluctant to assume care for patients with physical disabilities.^{7,26} Factors that exacerbate this limited professional knowledge and confidence in providing care include:

- Lack of education and exposure in training leading to knowledge gaps
- Low prevalence in practice limiting opportunities to gain and use new knowledge and making the financial and time-commitment to continuing education difficult to justify
- Lack of easily accessible practice tools/guidelines, and
- Lack of training on the use of specialized equipment, when it is available

ATTITUDINAL BARRIERS

Attitudinal barriers impede access to care in the following ways:

- Primary care providers may have negative attitudes toward disability that impacts the quality of the care they provide²²
- In turn, patients with physical disabilities often have less confidence in their physician's ability to provide appropriate care for their needs²⁷ and may seek care elsewhere such as in the

emergency department

SYSTEMIC BARRIERS

Health system disincentives contribute to the challenges of primary care in the following ways:

- Lack of funding to increase accessibility
- Lack of appropriate remuneration for the time-consuming task of providing complex care^{28,29}
- Fast paced clinic schedules that can lead to inadequate physical exams and less focus on preventative care owing to competing health needs, and
- Lack of multidisciplinary team set up and difficulty in accessing allied health.

PRACTICAL APPROACH TO CHALLENGES IN TREATING PATIENTS WITH PHYSICAL DISABILITIES IN THE PRIMARY CARE SETTING¹

BREAKING DOWN PHYSICAL BARRIERS: IMPROVING OFFICE ACCESSIBILITY

The Accessibility for Ontarians Disability Act, and other similar provincial legislations across the country, has helped make public and private spaces more accessible for Canadians with disabilities. Specialized equipment such as a wheelchair scale and ceiling lift/slings are helpful for the examination of patients with physical disabilities. There are many other office modifications that can be easily and cost-effectively implemented to improve the accessibility of clinics. Below is a list of potential clinic modifications that can make your office more accessible for patients with physical disabilities:

PARKING	Designated parking spots for use by persons with a disability close to the building with curb cut outs to facilitate easy access from the parking lot to the building.
ENTRANCE	Ramp with railings or a lift to access the door. Automatic door that accommodates the width of a wheelchair (approximately 37.5 inches).
WAY-FINDING SIGNS	Clear and simple signage to indicate the location of the office, washrooms and exit. Consider using contrasting colours, graphics and braille on signage.
WAITING ROOM AND RECEPTION AREA	Space available to park a wheelchair. Firm chairs with armrests for those who have difficulty transitioning from sitting to standing.
EXAMINATION ROOM	Adequate door width and floor space to maneuver. Railing/supports to assist with patient transfers. Mechanical lift. Portable examination equipment. Height-adjustable examination table that can be lowered to height of wheelchair seat (approximately 17 to 19 inches from ground).
WASHROOM	Accessible washroom outfitted with grab bars and emergency call bells. Sink, soap, paper towel dispensers should be at wheelchair accessible height. Enough space to maneuver a wheelchair.
STAFF TRAINING AND APPOINTMENT TIMES	Accessibility for Ontarians Disability Act (AODA) training for staff. Appropriate documentation of patients' special needs relating to sensory or mobility impairments, transfer methods.
MISCELLANEOUS	Consideration of folding platform/wheelchair scale and walker.

Adapted from "Making your office accessible for patients with mobility impairments"¹

Approximate cost associated with common assistive devices used in the office are listed below:

EQUIPMENT	ESTIMATED COST, \$
Height-adjustable examination table	6000
Wheelchair scale	3400
Ceiling lift and sling	1800
Grab bar* (18 to 24 inches long)	40
Emergency call bell	800

*This does not include the cost of installation, which might vary across service providers.

From "Making your office accessible for patients with mobility impairments"¹

In terms of transportation, as above, it is important to have designated parking spots close to the building for persons with disabilities. Furthermore, many patients are reliant on municipal-run special accommodation buses, which may be late in getting patient to appointments; advising staff to book longer appointments for patients using this form of transportation can help combat this potential problem. Patients should also be made aware of approximate appointment duration to facilitate their planning of an appropriate pick up time.

BREAKING DOWN KNOWLEDGE BARRIERS: RESOURCES AND SUPPORTS

For primary care providers, a perceived lack of knowledge combined with a low prevalence of physically disabled patients encountered in practice is a commonly cited barrier to caring for this population.³⁰ However, primary care providers can offer their broad knowledge base and expertise that is highly applicable to patients with physical disabilities, such as preventative care, mental health, pain management, and knowledge of the community that is valuable in maintaining overall health and well-being.

SUPPORTING PATIENTS TO PREPARE FOR THEIR FIRST APPOINTMENTS

Implementing tools in your clinical workflow that encourage patients to identify their key concerns and questions before coming in for their appointment can help to ensure that a patient's most important concerns are identified and discussed during their visit.

For example, this SCI Primary Care Toolkit was developed by the Mobility Clinic to help patients with Spinal Cord Injury (SCI) prepare for their first appointment.

SCI Self Management – Primary Care Checklist
SUMMARY SHEET

(please give this sheet to your healthcare provider)

1. THINGS I WANT TO DISCUSS WITH MY HEALTH CARE PROVIDER

i. Issue/Problem: _____

Details/description: _____

My Action Plan: _____

ii. Issue/Problem: _____

Details/description: _____

My Action Plan: _____

iii. Issue/Problem: _____

Details/description: _____

My Action Plan: _____

DETAILED CHECKLIST

2. BLADDER

How do you empty your bladder?
 Clean intermittent self-catheterization (IC)
 Indwelling ("Foley") catheter
 Reflex voiding with external (condom) catheter
 Suprapubic catheter with:
 Continuous drainage Intermittent drainage
 Spontaneous voiding with some voluntary control
 Other: _____

How often do you typically empty your bladder each day?
Times per day: _____
Overnight: _____

Has the way you empty your bladder changed in the last year?
 No Yes—Details: _____

How much fluid do you drink each day?
_____ litres (1 glass=250 ml)

List types of fluid (eg water, coffee/tea, alcohol): _____

How many urinary tract infections (UTIs) have you had in the last year?
 0
 1-2
 3-4
 5 or more

Have you experienced any of the following symptoms recently?
 Difficulty passing catheters/bleeding
 Increased straining or time to pass urine
 Frequent catheter blockages
 Sediment or blood in urine
 Leakage, urgency or less warning before voiding
 Higher urine volume than usual
 Increased bladder spasms or lower abdominal discomfort
 Increased episodes of autonomic dysreflexia or spasticity

Have you had any surgical procedures affecting your urinary system (eg stone removal, bladder augmentation, sphincterotomy)?

3. BOWEL

How do you empty your bowel?
(check all that apply)
 Spontaneous/voluntary evacuation
 Reflex stimulation with evacuation using:
 Enema Suppository Digital stimulation
 Manual evacuation
 Other (eg colostomy, sacral root stimulation): _____

How often do you empty your bowel?
 Daily
 Every second day
 Three times weekly
 Other: _____

When do you perform your bowel program?
 AM
 PM

On a typical day, how long does your bowel program take?
 Less than 15 mins.
 15-30 mins.
 30-45 mins.
 45-60 mins.
 More than 1 hour

What is your stool consistency usually like?
 Smooth, well-formed
 Hard, small lumps
 Loose, poorly-formed, watery
 Both hard and soft segments
 Other: _____

Has your diet changed recently?
 No Yes
Details: _____

Has your bowel routine changed significantly in the past year?
 No Yes—Details: _____

BREAKING DOWN ATTITUDINAL BARRIERS: CHANGING THE WAY WE THINK AND TALK ABOUT DISABILITY



The **QUICK & DIRTY** On Disability Word Choices

Sometimes you see the words **“impairment”** (referring to limited function) or **“handicap”** (referring to the limitations on day-to-day activity that result from the disability).

It is recommended to use the general term **“disability”**. For example: **“The person has a disability.”** And if there is a need to be more specific then, for example, say: **“he/she has a spinal cord injury”, “has paraplegia”, or “has loss of muscle function”,** etc – over the term **“impairment”**. In today’s word choices **“handicapped”** is never ok unless you are playing golf.

Another example would be to say: **“A person’s disability impacts his/her ability to drive”, or “A person needs more time to get dressed because of his/her disability”.** etc.

Sometimes you may hear/see the term **“the disabled”**

- Use **“People with disabilities”** instead. It is important to put the person first and not the disability.

Some people will say: **“confined to a wheelchair/ wheelchair-bound”**

Wheelchairs liberate rather than confine; they provide mobility; Substitute with **USES** a wheelchair

Think about words that you might use casually such as **“retard”, “spastic”, “spaz” “mental”**

These words are pejorative, specifically using disabilities to put others down.

“Suffered, stricken, afflicted”
– These are all words that solicit emotion and contribute to judgment of a person’s situation. Unless a person says he/she is suffering, it is not anyone’s place to assume that he or she is.

Use instead **“sustained”** or **“has a particular condition”** (i.e. sustained an SCI, has a brain injury) and then describe the resulting disability.)

“Invalid” – sometimes used to describe someone with a disability

To be avoided. This word confuses disability with sickness and it is the opposite of valid!

To say that someone **IS** spinal cord injured or **IS** arthritic or **IS** epileptic defines them only in terms of their disability.

It is better to say: HAS an SCI, HAS arthritis, HAS epilepsy, etc.

Sometimes people use terms such as **“physically challenged”, “differently abled”, and “special”**

All of these attempt to side-step the person’s disability. By trying to call a disability something else, it leads to the impression that disability is not ok.

“Able-bodied” is a term sometimes used to describe people who don’t have a disability.

Please avoid. The inference is that one person is able/capable and the other is not. Please use **“does not have a disability”** or **“without a disability”**.

For example: **“The race is for people with and without disabilities”.**

As per word choices for people with spinal cord injuries

Please use: **“a person with a spinal cord injury”** or more specifically, **“a person who has paraplegia”** or a **“person who has quadriplegia”**. Don’t use **“the person is paraplegic / quadriplegic.”** The disability should not define the person...

Use: **“The person has paraplegia/ quadriplegia.”**

Attendant Care

Please use **“Attendant services.”** To suggest that a person is being provided care is presumptuous and could be considered paternalistic.

A service is provided and only the person receiving it can determine whether care was also provided.

BREAKING DOWN SYSTEMIC BARRIERS: A WORK IN PROGRESS

Across Canada there are both federal and provincial initiatives to improve accessibility for individuals with disabilities. For instance, in Ontario, legislation exists mandating all medical practices to be fully accessible by 2025, in an effort to improve access to primary care for persons with all disabilities. Potential modifications to the physical environment and associated cost were listed above. As part of improving care for these patients, it is important for all staff to have awareness and sensitivity regarding accessibility for patients with disabilities. In Ontario, the training modules can be accessed on the Accessibility for Ontarians Disability Act (AODA) website; they are free of charge and take less than 15 minutes to complete.

CARE PARTNER ISSUES

Having a physical disability can impact all aspects of an individual's life; the effects may be far-reaching and will affect care partners. Individuals may require assistance from a partner, spouse, or family member to provide care and support. Care partners may have to assist with many of the activities of daily living (e.g. personal hygiene)³¹ Studies have shown that care partners of individuals with severe disabilities encounter many different problems, including role overload, lack of information, financial strain, impaired quality of life, changes in health status, and emotional problems.^{32,33}

It is important to periodically check-in with care partners for individuals with physical disabilities. Care partners may accompany patients to their medical appointments, which provides an opportunity to address issues that may be facing the caregiver. It is important to discuss health issues pertaining to the patient as well as the care partner (from the care partner's perspective). Interventions that target both the care partner and the patient have been shown to decrease symptoms, reduce depression and significantly improve quality of life. These interventions can include strategies to help manage medical and functional limitations, enhance support, reduce social isolation, and encourage self-monitoring of symptoms. There are significantly fewer health symptoms and the care partner-care recipient dyad experienced less depression than interventions that target only the care partner.^{4,34}

There are a number of studies investigating quality of life, depression, physical stress, burnout, fatigue, anger and resentment, and perceived burden of caregivers,³¹⁻³⁸ and it is important to take the following into consideration when checking in with and treating care partners. These recommendations are made based on interviews with care partners.

CARE PARTNER BURNOUT

- Burnout consists of emotional exhaustion, depersonalization, and a sense of a lack of personal accomplishment^{9,39}
- Consider whether the family has other dependents (children, pets, and other)
- This may occur any time post-injury
- Other times when burnout can surface
 - Change in number of dependents (new baby, pet, etc.)

- Increase in needs of the individual with a disability or dependents, even if temporary
- Increased stress in care partner's life due to job, family, etc.

'TAKING IT EASY' OR RESPITE

- It may be challenging for the care partner to 'take it easy' or to receive respite
- If the care partner must 'take it easy', consider what home care services, financial resources, or other resources will be required
- Often there is not another adult without a disability at home to do tasks that are done by the care partner such as mowing, shoveling, and putting out the garbage

CARE PARTNER MEDICAL ISSUES

- A care partner may be **more** or **less** likely to bring up medical concerns to their doctor depending on the individual
- A care partner may be **less** likely to bring up medical concerns in situations such as:
 - They feel unable to take time for their own health and hope the problem resolves itself
 - Their issue doesn't seem as serious as the individual with the disability's 'real' medical problems
- Conversely, they may be **more** likely to bring up medical concerns in situations such as having a need for attention when they feel the individual with a disability is always the focus
- They may feel added pressure to be healthy and not get injured because of their role as caregiver and main house keeper
- Muscle soreness, muscle strains, and lower back pain are more likely to be an issue
 - Consider massage therapy or physiotherapy treatments
 - Female care partners are likely doing more and heavier lifting compared to their non-caregiving peers
 - May need to be taken into consideration during times of illness, recovery and/or pregnancy

PSYCHOLOGICAL ISSUES

- Ask the care partner and care-recipient about potential emotional and physical abuse on a regular basis, regardless of gender
- Individuals with physical disabilities may experience mental health issues that the care partner has to support
- Care partner receive praise for supporting an individual with a physical disability
 - This can make it difficult to admit or discuss their own mental health issues
 - May benefit from counseling as a place to talk freely about issues they are experiencing

This manual and accompanying online modules can help with the nuances in assessing and managing many of the common issues encountered in primary care for patients with physical disabilities. These informational sections, in combination with specialist consultation, will enable the primary care provider to better and more confidently manage this population. The last section of the manual is a list of online resources that can be helpful for the primary care provider and the patient.

VIRTUAL CARE

With the onset of the COVID-19 pandemic, many healthcare providers had transitioned to virtual care, interacting with patients over the phone, and using audio or video conferencing applications to provide safe and efficient care.⁴⁰ With the increased need for timely access to healthcare, along with an aging population and a shortage of healthcare professionals, there has been an increased interest in virtual care and digital health strategies beyond their use in the pandemic.⁴¹ With the widespread use of virtual care modalities, the Ontario provincial government has rolled out billing codes to ensure due compensation for phone call and videoconferencing visits.⁴⁰ And now, with the expansion of virtual care, several telemedicine and videoconferencing options are available to healthcare providers.⁴²

VIRTUAL CARE OPTIONS

- OTNInvite
- Microsoft Teams
- Microsoft Skype
- Apple FaceTime
- Google Hangouts
- Zoom

BENEFITS OF VIRTUAL CARE

- Support continuity of care
- Better access to healthcare and increased patient satisfaction
- Convenience, time savings: patients do not need to account for transportation to/from a visit
- Cost-savings – patients do not require specialized transportation services or time off work
- Decrease avoidable in-person visits
- Have option to schedule in-person follow-up when necessary
- Reduced exposure
- Connect with underserved or rural populations, enabling patients to receive care when they might not otherwise be able to
- Resources and access can spread beyond "front door" into farther regions, province, country etc.
- Collaborative care through group visits and secure messaging
- Improve staff productivity

POTENTIAL BARRIERS OF VIRTUAL CARE

- # of mobility clinic assessments/visits or follow up visits that require physical exams
- Patient technical literacy

- Patients access to devices
- Patients access to internet
- Patients access to secure, private space for virtual visits
- Billing codes & remuneration

CONSIDERATIONS FOR PRIVACY AND CONFIDENTIALITY

- Obtain patient consent
- Conducting visit in private setting
- Using encrypted virtual care platforms

The Mobility Clinic has been using virtual care options prior to the start of the pandemic. Providing a virtual option for those with mobility issues helps to decrease barriers to access to care, including transportation to a clinic. Working with the eHealth Centre of Excellence, we have created virtual care workflows for the clinic, including the process for eReferral appointment booking and confirmation through Ocean. Important things to note are patient consent to receive emails and virtual care, confirming appointment details, and ensuring appropriate technology is available to the patient.

The Mobility Clinic has been using OTNInvite to conduct virtual visits. It is a secure method with integrated billing. Below are the steps to schedule an appointment with a patient through OTNInvite.

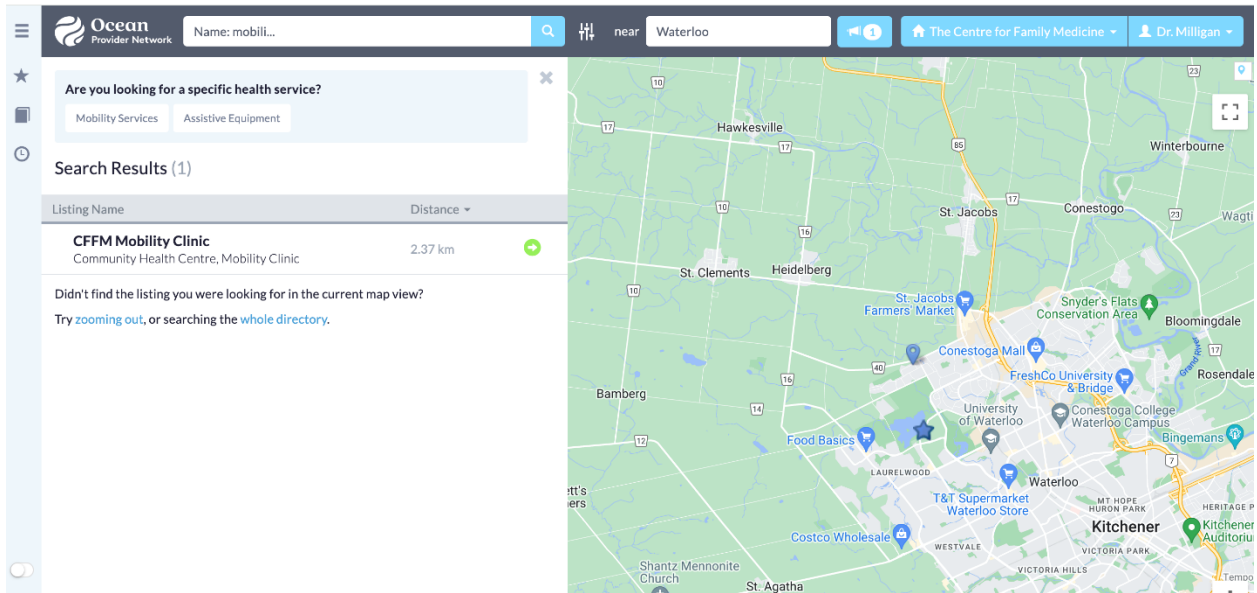
E-CONSULT AS A VIRTUAL TOOL OFFERED BY THE MOBILITY CLINIC

- Below is an example of Dr. James Milligan’s E-Consult Profile on OTN.

The screenshot displays the OTN profile for Dr. James Milligan MD. The profile is organized into several sections:

- Profile Header:** Shows the doctor's name, specialty (Family Medicine), and a 'View Lastest Update' link.
- Basic Information:** Lists CPID Specialty (Family Medicine), CPID License (Medical Board), Languages (English), and Clinic (Wellston Wellington).
- Services Offered:** Includes Videoconference Referrals (Average wait time: 4-8 weeks) and eConsult Advice.
- Indigenous Services:** Lists French Language Services as 'No'.
- TELEMEDICINE SERVICES:**
 - Telemedicine Service:** Family Practice/General Practice Medicine.
 - Telemedicine Service Details:** Primary care management of spinal cord injury and other physical disabilities.
 - Videoconference Referrals:** Dr. Milligan sees patients via videoconference.
 - Organization:** Centre for Family Medicine FHT (FHT).
 - Practice Address:** 108 Victoria Street South, Kitchener, Ontario, N2G 1G3.
 - Accept Referrals:** Yes, for spinal cord injury, stroke, and other physical disabilities.
 - Accept Referrals for questions regarding spinal cord injury (SCI) and other physical disabilities in primary care:** Yes, things as types of private care for those with SCI, stroke, multiple sclerosis, pain management are examples. (Note: Dr. Milligan is not a physiotherapist/rehabilitation medicine specialist).
 - Only Accepted from States/Regions:** Other Countries.
 - Availability:** Contact office 519-763-8223.
 - Scheduling Information:** Requires referral from family physician and completion of our referral form.
 - Clinical Protocols and Forms:** Includes links for 'Add New'.
 - Telemedicine Contact:** Includes links for 'Add New'.
 - Patient Site Requirements:** Support and Resources, Medical Permission (Dental Exam Camera, Telehealth, e-Visit Setup, Document Camera, Laptop).
- eConsult Advice:** Dr. Milligan answers clinical questions online via eConsult.
 - Accept eConsult Requests:** Yes.
 - Patient Eligibility:** Accepts referrals for questions regarding spinal cord injury (SCI) in primary care, such as things as types of private care for those with SCI, stroke, bladder, spasticity, pain, mobility are examples. (Note: Dr. Milligan is not a physiotherapist/rehabilitation medicine specialist).
 - Only Accepted from LHM's / Regions:** Other Countries.
 - Relevant Settings:** (None listed).

- External providers can send referrals to the Mobility Clinic via Ocean:



New Referral - CFFM Mobility Clinic

Patient Information

Surname: Mobile #:

First: Home #:

DOB: Business #:

Gender: Male Female Other Email:

HN: province health number VC

Address: ON

* Indicates a required field

Patient Information

Alternative Contact (If necessary):

Relationship:

Home Phone Number:

Work / Cell Phone Number:

Patient requires a mechanical lift to transfer

Referring Provider is not Primary Care Provider

Diagnosis / Medical History *

Reason for Referral *

Select all that apply:

General Assessment

Bowel / Bladder

Pain / Spasticity

Skin Breakdown / Wound(s)

Cervical and Breast Cancer Screening Initiative

Other

Include CPP

Personal Health Information that is medically relevant has not been disclosed at the request of the patient.

Referrer's Information

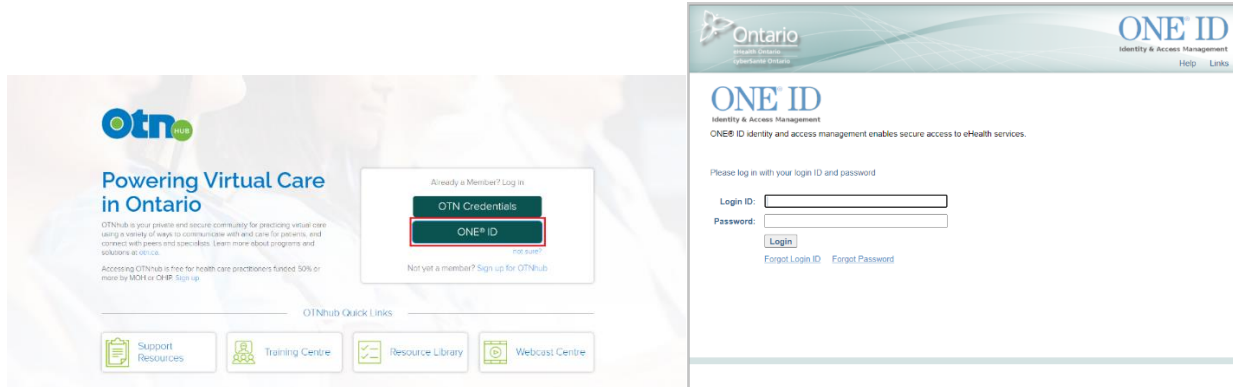
Site Name: The Centre for Family Medicine
Address: 10 B Victoria St. S.
City: Kitchener
Province: ON
Postal Code: N2G 1C5

Phone: 519-783-0022
Fax: 519-783-0032
Billing #: 024058
Professional ID: 86353
Signed: *James Milligan*
Role: Family Physician

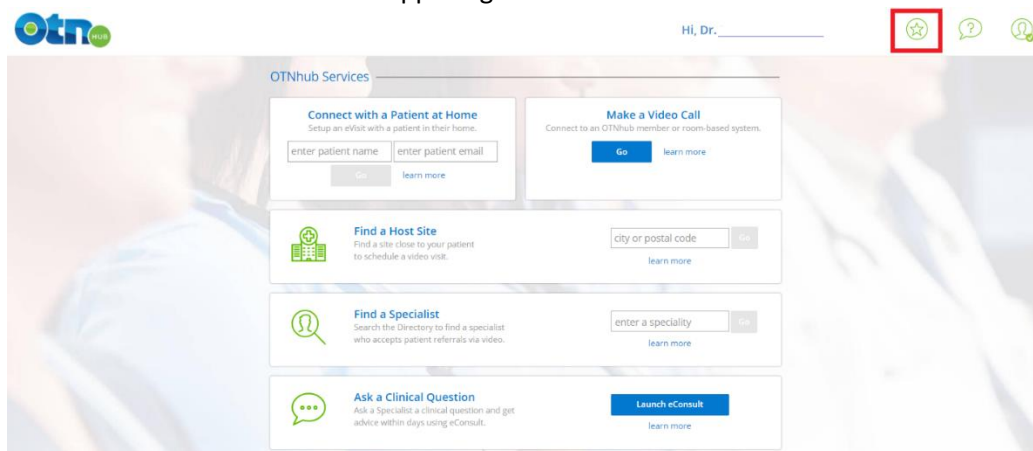
Copy of referral and status updates to:

SCHEDULING AN OTN VIRTUAL APPOINTMENT

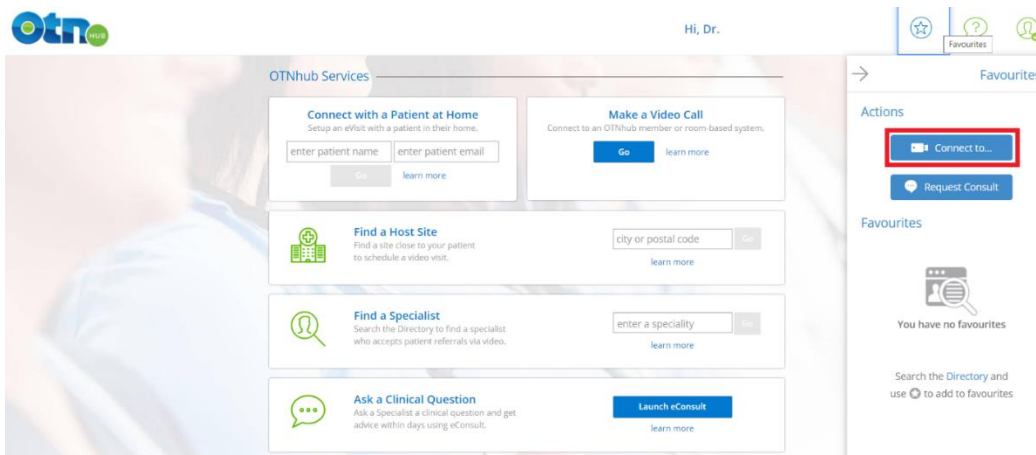
1. Go to www.otnhub.ca and log in using your ONE ID



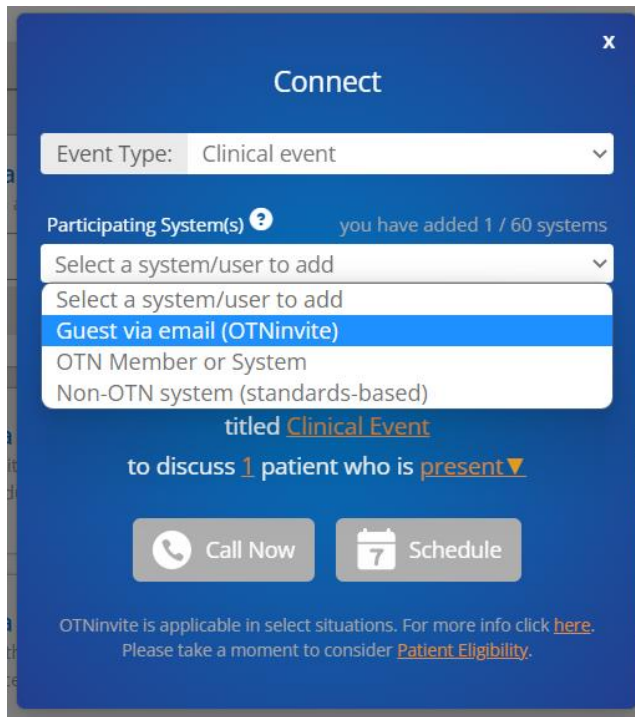
2. Click the "Favourites" star in the upper righthand corner



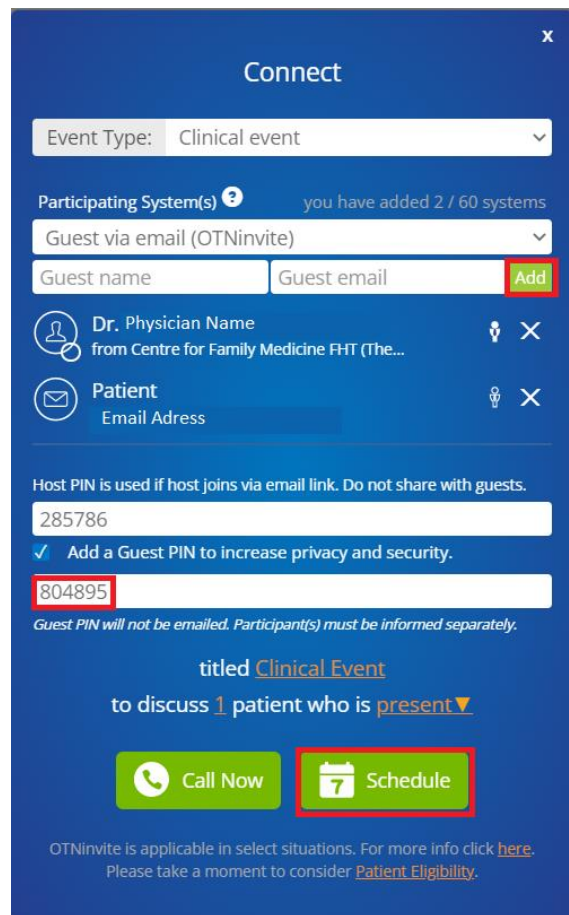
3. Select "Connect to..."



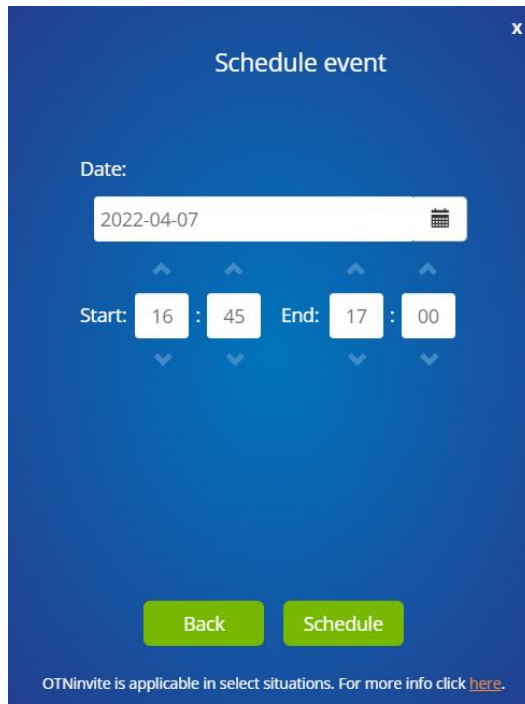
4. Select "Guest via email (OTNInvite)"



5. Fill in patient name and email address and select “Add”. Check “Add a Guest PIN” and make note of the 6-digit PIN. This will need to be shared with the patient so they can attend the appointment. Then click the “Schedule” button at the bottom.



6. Schedule appointment. Make note of the 24-hour clock.



7. Confirm the appointment details.

Schedule Event

Are you sure you want to schedule this event?

Time: Apr 07, 2022, 16:45 - 17:00
 Consultant: Dr. **Physician Name**
 Consultant system: Dr. **Physician Name**
 Participating System(s): Patient (**patient email**)
 Administrative contact: *Not provided* [Update](#)

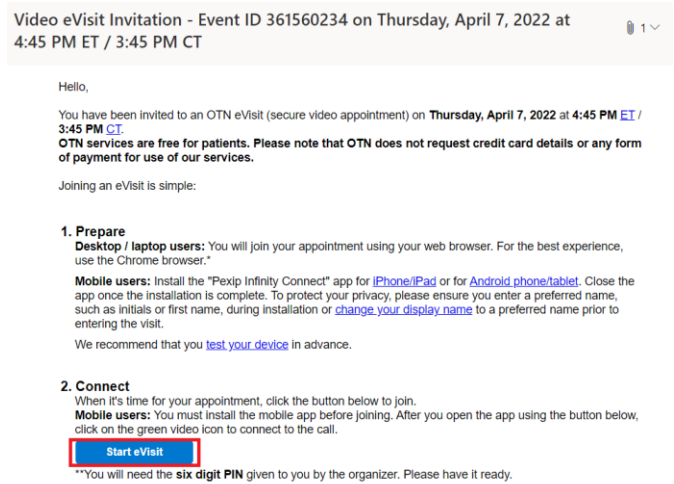
The event will be sent to any participants invited by email. If you've invited participants by email, the event cannot be modified once it has been created.

If you want to give the attendees additional notice about the event, a patient handout which includes the host's administrative contact is available in the event details. (The handout will not be sent to the patients automatically).

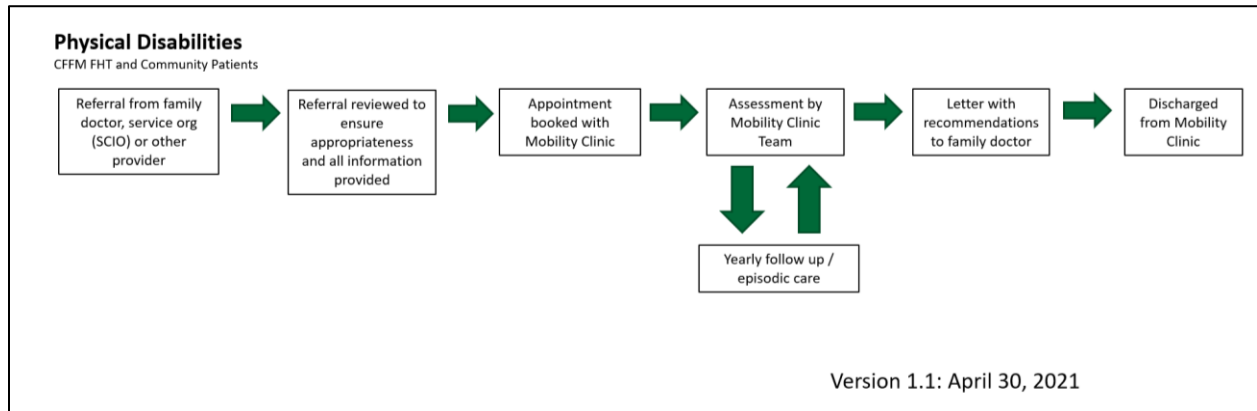
View the patient handout in a new window

[Schedule](#) [Cancel](#)

8. The patient will receive the following email. They will need the 6-digit PIN to join the visit.

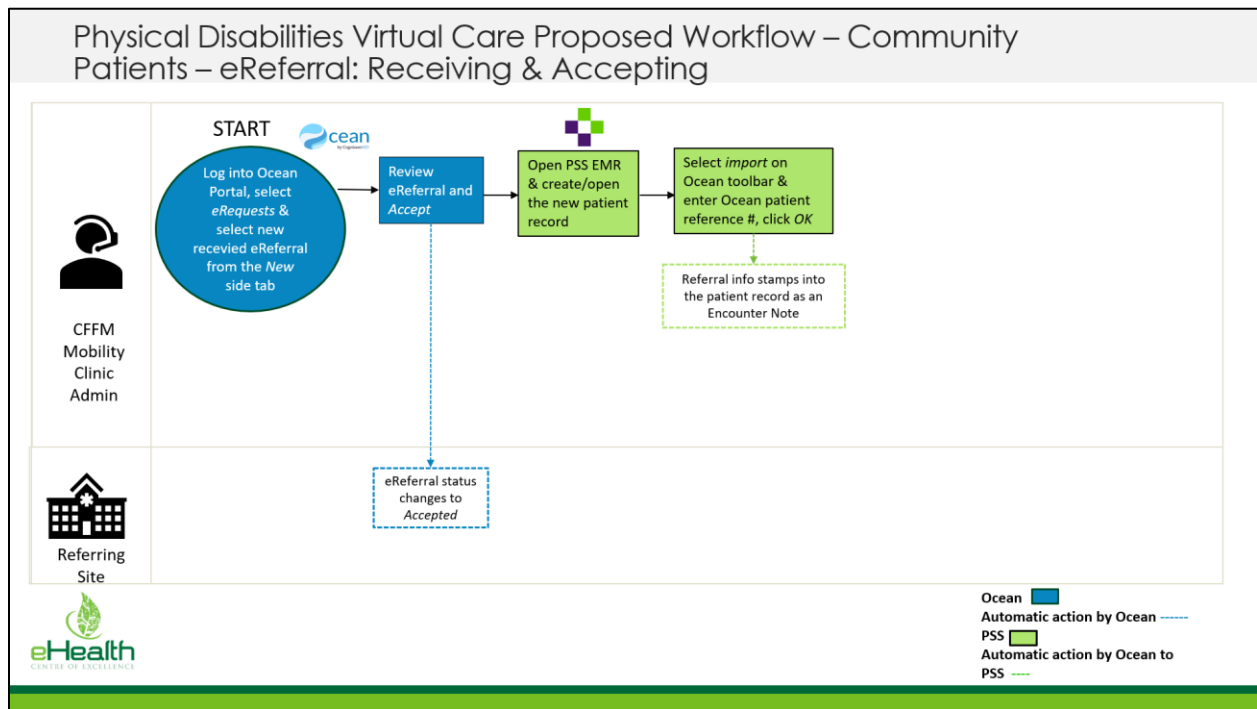


EXISTING MOBILITY CLINIC WORKFLOW

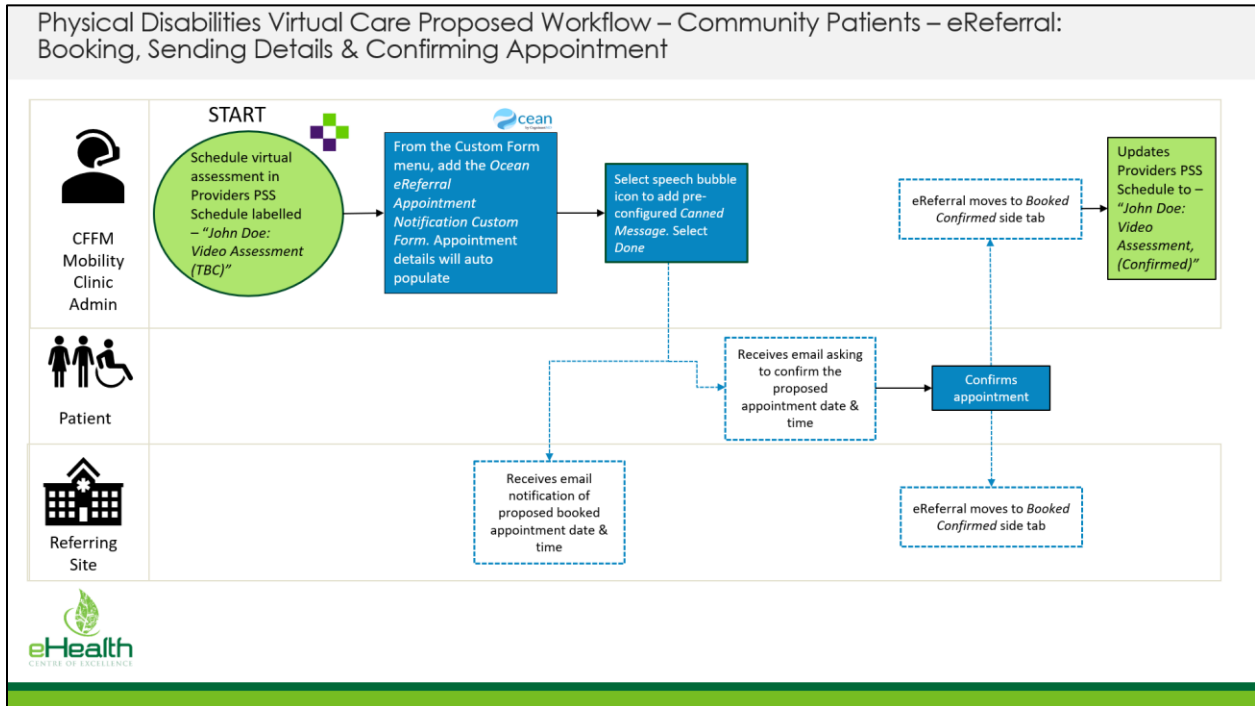


VIRTUAL CARE PROPOSED WORKFLOW – eREFERRAL FOR COMMUNITY PATIENTS

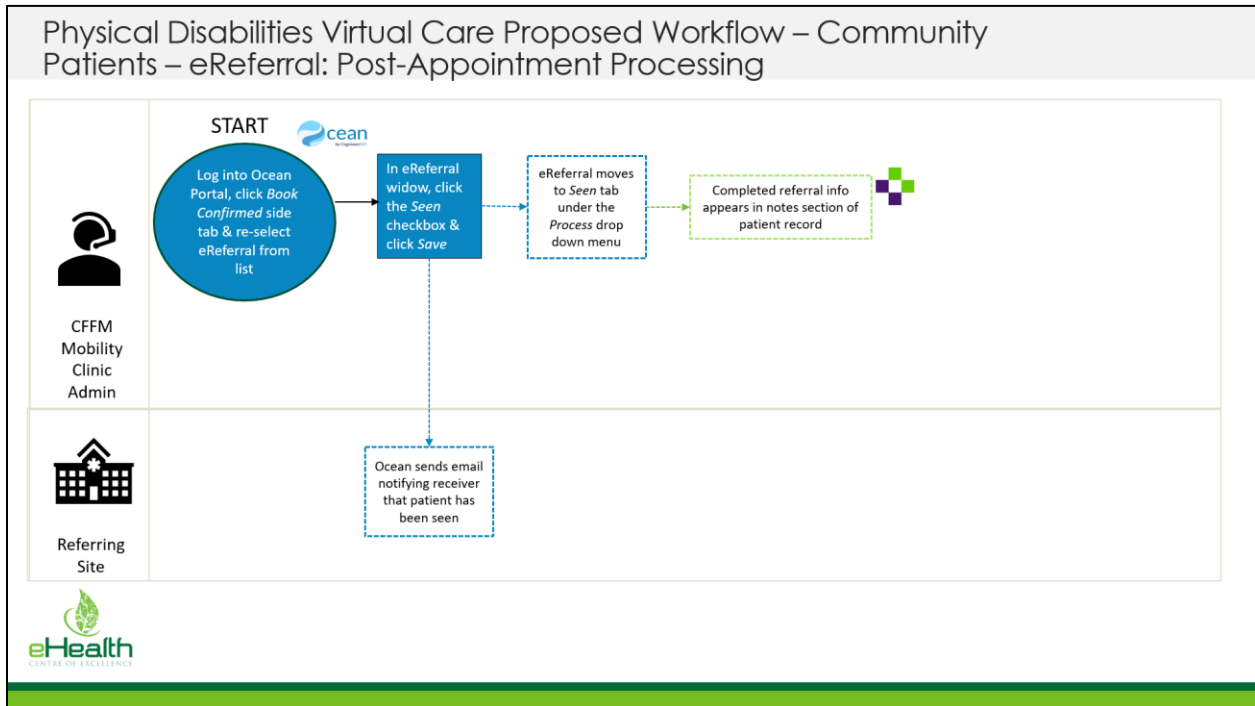
- **Receiving & Accepting eReferrals**



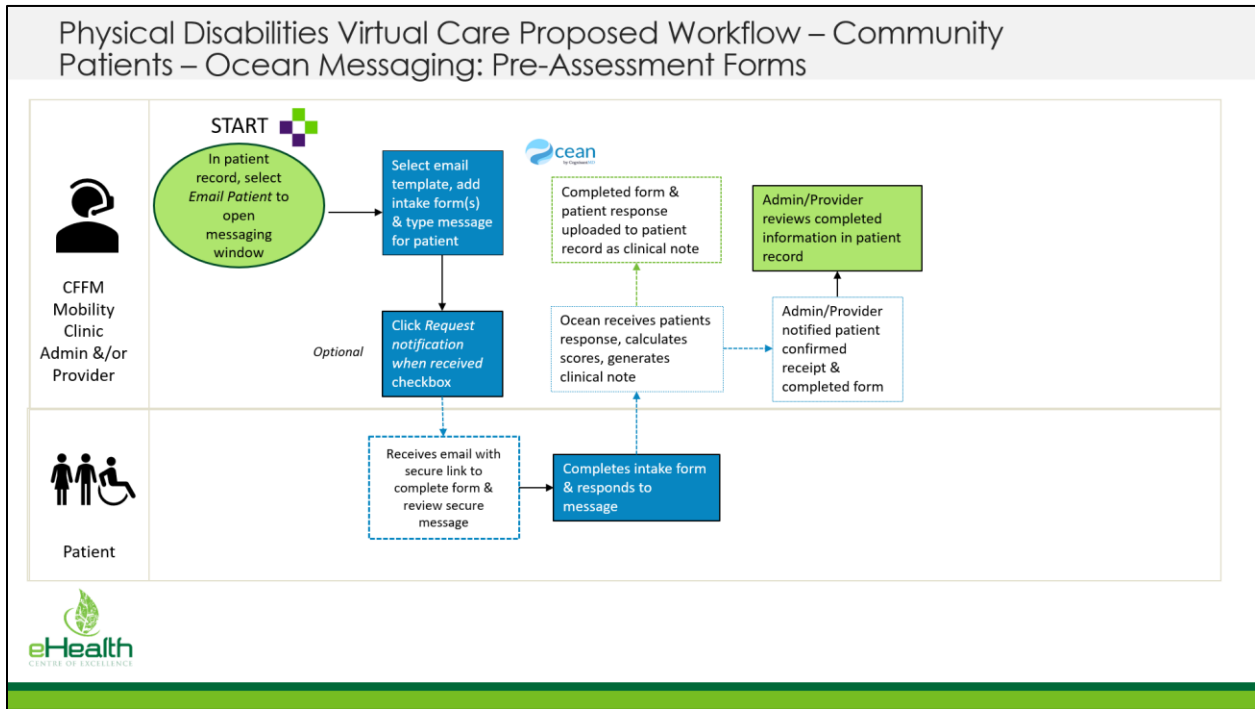
- **Booking, Sending Details & Confirming Appointment**



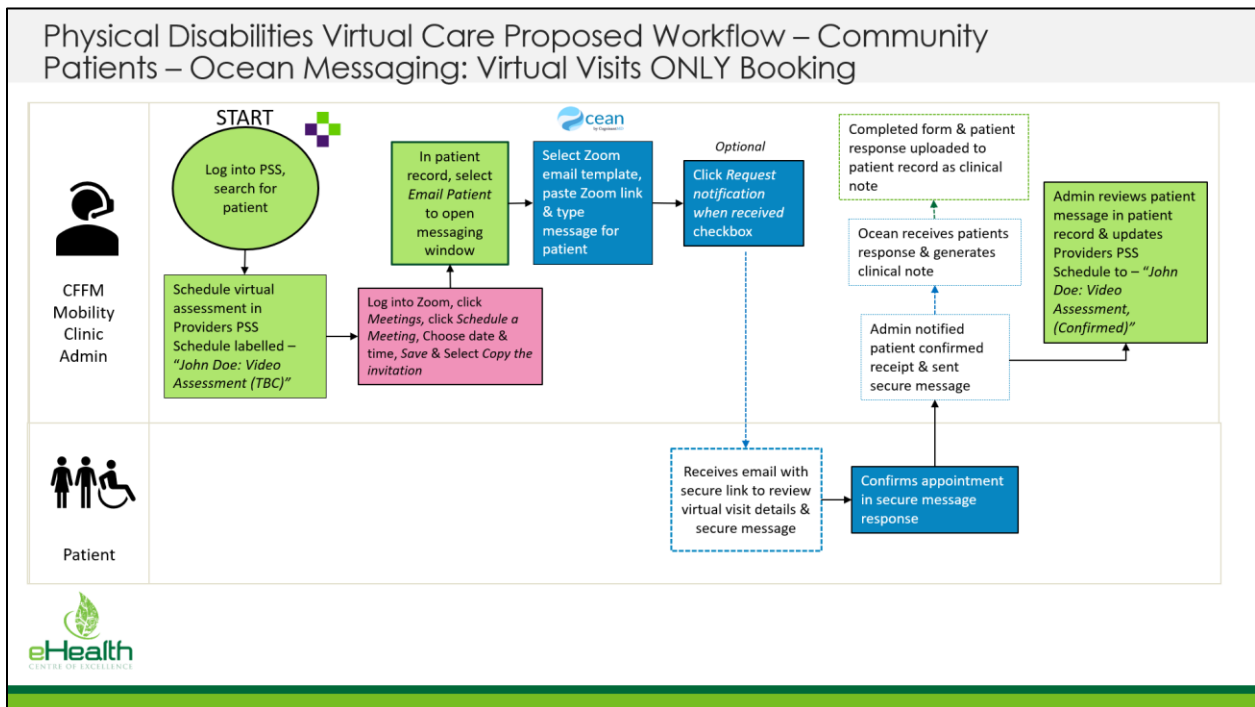
- **Post-Appointment Processing**



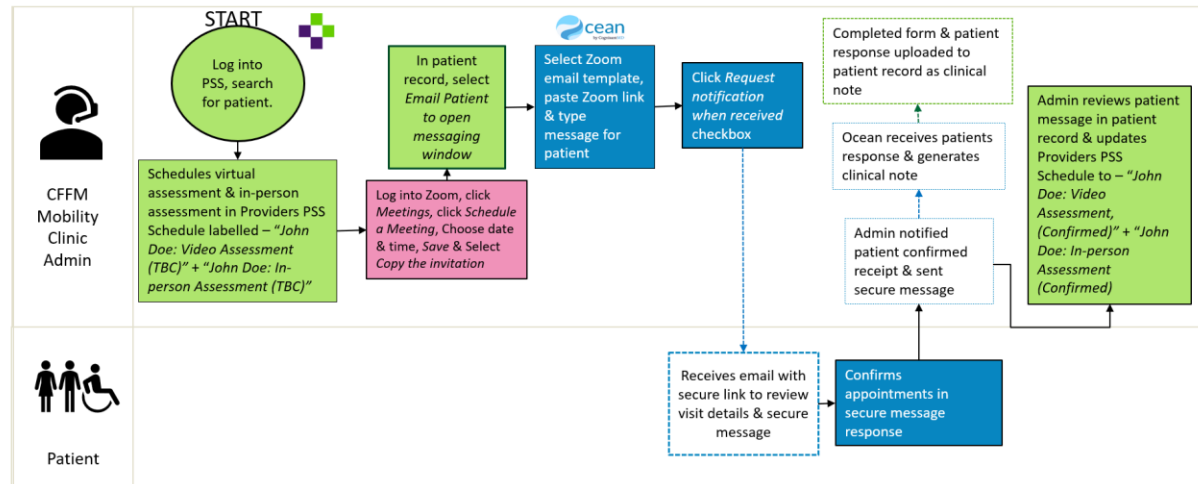
- **Ocean Messaging: Pre-Assessment Forms**



- **Ocean Messaging: Booking virtual visits**

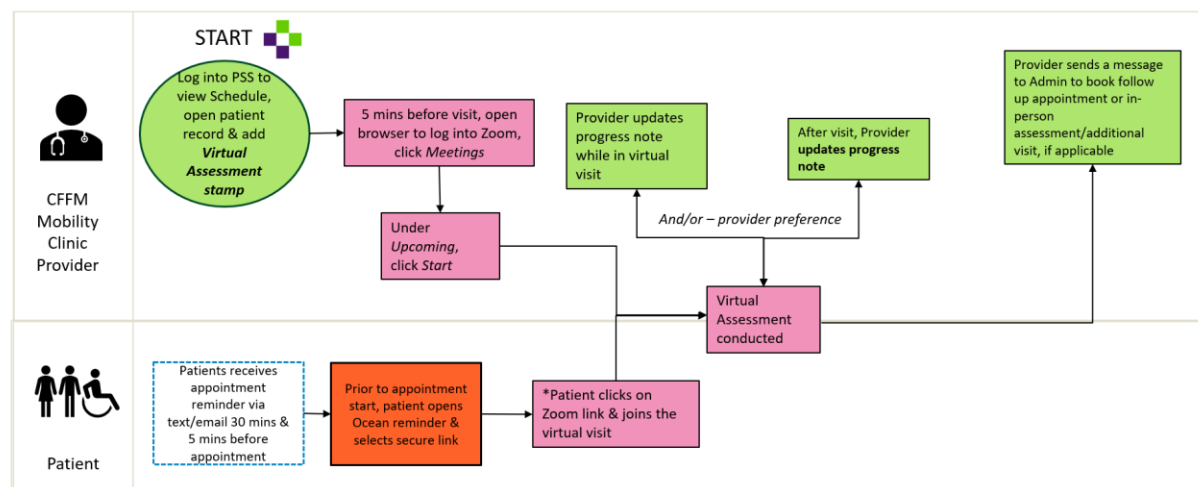


Physical Disabilities Virtual Care Proposed Workflow – Community Patients – Ocean Messaging: Virtual Visit & In-Person Booking



- **Conducting a Virtual Assessment with Appointment Reminders**

Physical Disabilities Virtual Care Proposed Workflow – Community Patients – Conducting a Virtual Assessment with Appointment Reminders



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