Supporting Mental Health After a Spinal Cord Injury

Background

A Spinal Cord Injury (SCI) is a life-altering event that often leaves patients and families in shock, denial, and disbelief. The stress of recovering from their injury and learning about the changes in their body can be overwhelming and grief provoking. After a spinal cord injury, patients and families may become overwhelmed physically, emotionally, cognitively, and financially. There may be long waits for specialized services and limited financial and benefit coverage. This can be very stressful for the individual and their family not only during the acute phase, but through the continuum of care and transition to the community. Depression and anxiety are the most common mental health concern after an SCI diagnosis. Approximately 40% of persons living with SCI report depression or mood problems (Praxis 2019). Persons with lived experience state that depression, anxiety, shock, and anger can happen at any time after an SCI, but often occur after transition to the community when support and routines may change. Early screening and on-going access to mental health and peer support can assist the patient and family throughout continuum of care.

Purpose of Guidelines:

The purpose of this document is to provide front line health care providers and physicians with guidance to assist and support patients (and their families) in maintaining optimal mental health after a spinal cord injury and throughout the continuum of care including transition into the community.

Key Messages:

- It is common for patients and families to experience shock, sadness, anger, frustration, irritation, confusion and grief after major loss or a significant change in health.
- Patients and families may have trouble absorbing and retaining all the information that is given to them. Healthcare providers may need to repeat information until they see that the patient and family are absorbing and understanding.
- Everyone's level and pace of acceptance regarding their injury can vary and they may or may not be ready to accept mental health or peer support.
- Symptoms of depression and anxiety are normal responses after an SCI.
- Patients should be given the opportunity to grieve; it is ok not to be ok.

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- Emotions can change depending on the situation, offer the patient time and space to process emotion.
- Refer to a spiritual care service to provide support to the patient during the grieving process. If spiritual care is not available referral to social work or psychology is appropriate.
- Involve AHS Indigenous cultural helpers, traditional wellness counsellors, Indigenous health and hospital liaisons as needed and where possible.
- Connecting with peers (people with lived experience) who are in similar stages of their life (such as parenting or other life transitions) can help improve a patient's outlook and provide hope.
- Provide information for patient and family to connect with SCI Alberta. This can happen at any point during the patient's journey.

Common Mental Health Concerns after a Spinal Cord Injury

Anxiety:

Anxiety is a normal reaction to an SCI and what life may look like afterwards. However, when anxiety becomes overwhelming and interferes with daily functioning the patient may require further assessment and treatment from a mental health practitioner (i.e., social work, psychology, or psychiatry). Anxiety disorders are characterized by anticipation or worry about future threat and a strong desire for control and order and are typically accompanied by symptoms such as muscle tension, vigilance, and cautious or avoidant behaviors. Individuals may feel overwhelmed, become easily angered or irritable, and/or become reactionary to a situation or trigger (not necessarily related to their SCI) due to a perceived lack of control and/or threat. This has the potential to cause isolation for the individual. Clinical anxiety disorder symptoms are persistent (typically lasting 6 months or more); the fear is typically excessive to what would be expected (taking cultural and contextual factors into account); and interfere with cognitive, emotional, social, and physical functioning. The General Anxiety Disorder (GAD) 7 is a tool that is used to assess the severity of generalized anxiety.

Depression:

Depression is one of the most common mental health concerns in persons with an SCI. Feeling sad is a normal reaction to stress and loss. However, when these feelings become severe, prolonged, and impair daily functioning, further assessment and treatment may be indicated. Other symptoms include inability to feel joy or pleasure, and changes to sleep and appetite because of low mood and little interest. In acute care or in-patient rehabilitation, symptoms may be identified by a bedside clinician, and subsequently, the patient may be referred to a mental health professional such as psychiatry, psychology, or social work. The Patient Health Questionnaire (PHQ-9) is often used to screen for the presence and severity of depression symptoms.

Post-Traumatic Stress Disorder (PTSD):

An SCI often involves exposure to a life-threatening traumatic event. PTSD is viewed as the inability to recover from the fear experienced during or after a shocking, scary, or dangerous event. To be diagnosed with PTSD a person must have all the following symptoms:

- Intrusive or re-experiencing memories or images such as bad dreams.
- Avoidance such as staying away from places, people, or items.
- Negative alterations in cognition (i.e., views of the world or of safety more globally) and mood such feelings of guilt or blame.
- Alterations in arousal and reactivity such as being easily startled or feelings of being on guard.

Patients should be screened for PTSD after the first month of their SCI. To qualify for a diagnosis of PTSD, an individual must have symptoms for at least one month that cause significant distress or impairment. Individual should be referred to a mental health professional for proper assessment and treatment.

Substance Use Disorder:

Substance use disorder is a disease that effects the brain and behavior and leads to the inability to control the use of substances. Often individuals with a substance use disorder have a co-existing mental health disorder such as anxiety, depression, or PTSD. Substance use disorder can impact length of stay, rehabilitation outcomes, decreased satisfaction, and increased risk of mental and physical health concerns such as depression, anxiety, pressure injury and UTI.

Individuals with substance use disorder should be referred to Addictions and Mental Health for further support and connection to addictions services such as peer support; addictions counseling, and other psycho-social resources. AHS staff should refer to the Psychoactive Substance Use policy. This policy provides direction on practices and strategies to support patients living with substance use.

Suicide:

Suicide ideation is common after SCI and is at least 3 times more common in persons with SCI than without. Suicidal thoughts and behaviors may be identified in the acute care or rehabilitation setting. It is important for healthcare providers to recognize warning signs and ask direct questions regarding suicide. Warning signs may include:

- Talking about death or suicide.
- Loss of interest in activities.
- Giving away possessions.
- Talk about being a burden.

Direct questions may include:

- “Have you had thoughts of taking your life?”
- “Do you have a plan to take your life?”

If an individual is actively suicidal, they should not be left alone, ensure someone remains with them and their safety is ensured. The patient’s most responsible healthcare provider (MRHP) should be contacted immediately. The individual may need expedited referral to psychiatry or psychology, and if in in-patient rehabilitation, may require transfer to an acute care mental health setting.

Providing Support to the Patient and Family

Involve Patient and Family:

- Acknowledge and validate that an SCI is a life altering event.
- Normalize the experience of distress, uncertainty, anxiety, sadness, and frustration.
- Patients and families may be in shock after an SCI diagnosis and may not be able to understand or absorb the information that is given to them.
- Ask the patient how they are doing. Ask the family how they are doing.
- Ask if they need / would like support.

- Ask the patient what coping strategies they have used (such as meditation, relaxation, or distraction), and how they can be supported.
- Offer mental health support throughout the continuum of care (from acute care to transition to the community) as their mental health and well-being may fluctuate. Normalize the use of mental health supports.

Be an Active Listener:

- Be an active listener by giving the patient your undivided attention and acknowledge what they are saying. Ensure you are facing the patient and maintain eye contact and be aware of non-verbal cues.
- Avoid matter of fact statements such as “you need to get used to this” or “this is now your life” as they are not therapeutic statements.
- Do not interrupt – allow the patient and family to finish what they are saying.
- Allow the patient and family to have room for hope with their diagnosis.
- Be mindful and genuine with your responses – use empathy and compassion. Acknowledge the patient’s and family’s feelings and emotions.
- Avoid statements like “I understand” or “I can only imagine how difficult this must be for you.” Instead acknowledge what they may be experiencing “I can never understand what you have been through, but I can respect it and acknowledge it”.

Create Awareness of the Supports and Information Available in Hospital and Online:

- Patients and families often state that they were not aware of resources such as peer support, that are available for them.
- Persons living with SCI state that they have found resources can be limited, especially in-patient treatment programs that can accommodate individuals with an SCI.
- Make patient and family aware of services and supports available, such as peer support, social worker, psychology, and spiritual care to enable informed decision making.

Offer Peer support:

- Peer support volunteers are individuals living with spinal cord injury who share their stories and the knowledge they have acquired over time, in efforts to help others as they begin their journey living with a spinal cord injury.

- Many people with lived experience have shared that speaking with a person that has transitioned to living well with an SCI is motivating and can provide hope; this is different than hearing the same information from someone without shared experience.
- Peer support should be offered early after the spinal cord injury once the patient is medically stable. Patients and families may not be ready to have peer support and refuse. It is important to continue to offer throughout the patients stay in hospital and rehabilitation.
- Peer support and a connection with the SCI community is an important aspect in transitioning from hospital to home. SCI-Alberta provides ongoing peer support, education, see link below to SCI-Alberta peer support program.
- Peer support volunteers have criminal record checks and have completed requirements to become an Alberta Health Services volunteer.

Resources:

Peer, Family, and Community Support:

Spinal Cord Injury Alberta

Spinal Cord Injury Alberta can assist patients and their families in providing a connection to peer support both in-hospital and in-patient rehabilitation, as well in the community.

- Peer Support Program – SCI Alberta (sci-ab.ca)

Patient Experience and Peer Support (Calgary zone)

This program is available to patients at the Foothills hospital and consists of volunteers with lived experience who provide hope and encouragement from a Peer perspective.

- For more information contact Patient Liaison Kasey.aiello@ahs.ca

Patient and Family Education:

The following links are resources that are available for patients and families.

- Coping and Adjustment to Spinal Cord Injury - Living With Spinal Cord Injury
- Grief and Grieving
- Preventing suicide
- Women's Mental Health After Paralysis

Staff Education:

- AHS staff My Learning Link – Trauma Informed Care

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