Transitions in Care for Patients with Acute Spinal Cord Injury

A spinal cord injury (SCI) is a life-altering event. Patients are often hospitalized for long periods of time and may move through several areas of the healthcare system (such as critical care, acute care, and in-patient rehabilitation) before transitioning back to the community. These transition periods can be stressful, frustrating, confusing, overwhelming, and/or challenging to navigate for patients and families for any number of reasons, some of which may include:

- Feeling left out and uninformed about what to expect about their care journey (for instance, when transitioning to in-patient rehabilitation).
- Long waits for specialized services, equipment, home renovations and/or relocation to more suitable accommodations as well as limited financial and benefit coverage.

Purpose of Resource:

The purpose of this resource is to outline special considerations for patients with acute SCI and their families through their initial healthcare journey, and to assist healthcare providers in supporting patients and families as they navigate through their transitions in care.

Key Messages:

1. Patients and families may have trouble absorbing and retaining all the information that is given to them. Healthcare providers may need to repeat information and/or provide them with resources to support their learning.
2. Communication to receiving care area should include the patient's unique care needs (e.g. neurogenic bladder, neurogenic bowel) and how they are being managed. Are they able to manage their condition independently, with assistance or guide their care?
3. Transitioning to home and community can be challenging as the skills patients learn while in rehabilitation may not always translate to the home or community environment.
4. Provide information for the patient and family to connect with Spinal Cord Injury Alberta (SCI-AB). SCI-AB can assist with transition to the community and provide education, connection to peer support and other community resources.
5. Clear and transparent communication between care teams and areas is vital. Patients and families find it difficult to repeat their story multiple times.
6. Ensure patient and family involvement with transition between care areas, facilities and in discharge planning.
7. Communication with patient and family should be at a language level that both the patient and family can understand (i.e., avoid using overly technical medical terms, take time and pace the interaction to match the patient and family's need, and/or use

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language interpreters for to communicate with those who do not speak English or speak English as an alternate language).

8. Involve AHS Indigenous cultural helpers, traditional wellness counsellors, Indigenous health and hospital liaisons as needed and where possible.

Patient and Family Involvement:

Patients with an acute SCI can be in the hospital and/or in-patient rehabilitation for many months before being ready to be discharged back to the community setting. Patients and their families are provided with vast amounts of information in this initial period of recovery, and they may not understand, remember, or integrate it for various reasons, such as:

- They may be experiencing pain, grief and/or other life stressors which can compound their ability to take in new information.
- They may feel overwhelmed with the amount of information or pace at which it is provided to them.
- They may feel excluded from care or discharge planning conversations, or the conversations occur at a language level that they do not understand.
- They may not speak English or speak English as an alternate language and don't understand the information provided to them.

Actions the healthcare team can take:

- Attempt to provide information at an appropriate time (i.e., when the patient is alert, when the patient's pain is controlled, when they are not rushing to a therapy, when they are emotionally regulated) and pace the information appropriately (i.e., avoid rushing). It can be helpful to have a family member present to support the patient's learning.
- Ensure patients and families are involved in care and discharge planning discussions.
- Patients and families may need to hear information multiple times. Check in with patients and families throughout discussions to ensure that they are understanding what is being said. Provide the patient and their family with an online education resource such as "Living with SCI", so they can refer to same if they forget or need clarification.

  Tip: Using a simple teach-back strategy (i.e., asking patients and families to repeat the information back to you in their own words) can support the team in knowing when they have integrated the information.

- Communication with patient and family should be at a language level that both the patient and family can understand (i.e., avoid using overly technical medical terms, take time and pace the interaction to match the patient and family's need, and/or use language interpreters for to communicate with those who do not speak English or speak English as an alternate language).
- Encourage patients and families to keep a journal of their questions so they can keep track of responses and review them as needed.
- Involve AHS Indigenous cultural helpers, traditional wellness counsellors, Indigenous health and hospital liaisons as needed and where possible.

Transition between care areas/units:

Throughout their healthcare journey, patients may transition to several care areas including critical care, acute care, and in-patient rehabilitation. Patients and families with lived experience have stated that it can be traumatic to repeat their story and experience as they transition between areas. They have also shared that they often feel uninformed about what they can expect as they move through the system.

Actions the healthcare team can take:

- Prior to/at time of transfer, provide detailed information to the receiving unit or site. This should include pertinent history as well as where patient and family are in their rehabilitation education.
- Communication to receiving care area should include the patient's unique care needs and how they are managed. Is the patient able to manage their condition independently, with assistance or guide their care?
- Ensure the receiving area is aware of the resources listed below to assist in providing care to the patient.
- Consistently provide patients and families with an accurate overview of the unit or site they will be transferred to and what they can expect once they arrive.

Transition to Community:

Transition from in-patient rehabilitation back to the community can be both exciting and distressing for patients and their families. Even though a patient may be physically ready for transition or discharge, they may not feel emotionally ready or confident that they can manage

on their own with their changed abilities related to their SCI. Preparing the patient and family early in their journey for transition can help build their confidence and ease fears.

Actions the healthcare team can take:

- **Connection to Spinal Cord Injury Alberta (SCI-AB)**
  SCI-AB is a non-profit organization focused on empowering persons with spinal cord injuries to achieve independence and full community participation. They support individuals through education, resources, and peer support. Introducing the services of SCI-AB early in the patient's journey can help the patient and their family prepare for transition back to the community. SCI-AB has Client Service Coordinators who can help patients and families navigate life after a SCI and provide connection to peer support.
- **Peer Support**
  Patients have shared that it is far more valuable to learn about their transition to living with a spinal cord injury from a person with lived experience (versus from a health care provider that does not have that experience). Many persons with lived experience have suggested the earlier the better as connecting with persons that have had an SCI for a period of time and that are living full productive lives can provide the patient optimism. Connecting them with peer support, and in particular someone who is in similar stages of their life (such as parenting or other life transitions), can help improve a patient's outlook, provide hope, and assist with transition back to the community. Patients and families may not be ready to engage with SCI- AB or peer support and refuse it, therefore it is important to continue to offer it throughout the patient's stay in hospital and rehabilitation.
- **Support opportunities for re-integration into community while in inpatient rehabilitation setting.**
  Support the patient to go out on pass if able and as appropriate (this may not be an option for all patients or available in all care areas). This will provide an opportunity to slowly reintegrate into the home and community environments and build confidence with skills such as transferring from wheelchair to car, accessing transportation or navigating public spaces. *Patients and families at the Glenrose Rehabilitation Hospital can stay in Independent Living Suite (ILS) to practice for transition back to the community.*

- **Equipment and home modifications**

  Both equipment and home modifications can be expensive and take time. Patients and families should be supported to consult with experts (OT, SW, SCI AB) when determining what equipment is needed for home and what renovations or relocations may be required to prevent unnecessary spending.

  - Consult Occupational Therapy or Physiotherapy with questions regarding appropriate equipment, home renovations, and/or adaptive devices.
  - An AHS social worker and/or a SCI-AB client service coordinator can support the patient and family with accessing funding sources and community resources and can assist with the application process.

- **Homecare**

  Homecare supports can be different for each individual and availability of homecare services can vary based on where the patient and family reside. While the patient is in hospital engage an AHS Transition Services Coordinator early once a patients care needs in the community have been determined.

- **Patients unable to return to their current living arrangement**

  Depending on the severity of the SCI and care-related needs, some patients may not be able to return home and may need to move into an assisted living facility or accessible housing. While the patient is in hospital, the team may consult with a Social Worker or Transition Services Coordinator to determine which type of living support is best suited to the patient's care needs.

- **Patients living in a rural community setting**

  Some patients may transfer to a hospital facility in their home community while waiting for inpatient rehabilitation or for home renovations to be completed. Rural sites may not have the equipment, expertise or staffing to support skills learned in acute care or inpatient rehabilitation. Individuals with lived experience have stated they lost the skills they acquired because they were not supported in using them.

  - Provide receiving site, patient, and their family with a detailed care plan of where patient is with their skills and education.
  - Ensure the receiving site is aware of the resources listed below to assist in providing care to the patient.

- If possible, provide receiving site with a contact clinician or resource they can access if they have questions.
- Ensure patient and family are aware of resources available including SCI-AB client services coordinators.
- Encourage patients to participate and direct their care.

- **Mental health support**

  Individuals living with SCI are at a high risk of developing anxiety and depression when they transition to the community. Individuals with lived experience often report experiencing emotions such as shock and anger at various points after a SCI, and particularly after transition to the community when support changes and daily routines are disrupted. Early screening and ongoing access to mental health and peer supports can assist the patient and family throughout continuum of care. For more information on mental health after a SCI refer to Supporting Mental Health after a Spinal Cord Injury.

  - Offering connection with SCI-AB early (and throughout) in the patient's healthcare journey can help them and their family prepare for transition back to the community.
  - When possible, advocate and support the patient to go out on a community outing and/or day or overnight pass home to help build confidence and skills.
  - Connect patients and families with mental health support (eg. psychologist, social worker, indigenous cultural helper) before transitioning to the community.

- **Discharge Summary**

  In Connect Care, the patients unique care needs and where they are in their education can be added to the Patients Discharge summary. A copy of the discharge summary should be given to the patient and family. The discharge summary is available to view on My AHS Connect for the patient, and in Connect Care and Netcare for receiving sites.

Resources

After a SCI, patients and families may become overwhelmed with the changes, and may have trouble absorbing and retaining all the information that is given to them. The following list of resources may be helpful for them to refer to both during their hospitalization and rehabilitation, as well as during or after transition to the community.

On-line educational resources for patients and families

- Living with SCI
- SCIRE Community (scireproject.com)
- Yes, You Can

Spinal Cord Injury Alberta (SCI-AB)

- Overview
- Peer Support Program information
- Contact information

Caring for Patients with a Spinal Cord Injury – Standardized Topics

- Autonomic Dysreflexia - Adult
  - Helping others understand your Autonomic Dysreflexia - Brochure
  - AD pocket card
- Neurogenic Bladder Management
- Neurogenic Bowel Management
- Pain
- Pressure Injury Prevention
- Spasticity
- Supporting Mental Health

AHS resources

- My Next Steps: Getting ready to leave the hospital (albertahealthservices.ca)

References

Alberta Health Services. Home to Hospital to Home. (2020). https://www.albertahealthservices.ca/assets/info/hp/phc/if-hp-phc-phcin-hthth-guideline.pdf

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