

Nursing Support Services Principles and Philosophy of Care for In-Home Respite Care Services

Nursing Support Services (NSS) is a medically focused respite nursing program that provides supplemental support for families/guardians of children with chronic, complex health conditions (birth to 19 years) to help each child and youth lead active, healthy lives in their home and school settings. As a provincial program NSS provides oversight in the respective five (5) health authorities within British Columbia (BC) whereby safe, quality care is provided to children/youth with medical needs who require the knowledge, judgement and skill of a licensed nurse for some aspects of their care in the absence of parent(s)/guardian(s).

There is no cost to families for this optional service. Referrals to NSS are made by a child/youth's physician or nurse practitioner licensed to practice in BC. NSS recognizes that children/youth living with medical complexity often require enhanced care services and supports that cross multiple sectors to meet their physical and psychosocial needs. As a program of care within BC's broader care delivery system, this document explains NSS's service delivery model and the philosophy of care that is the basis of our services and program's authority.

- As per the child's¹ eligibility for NSS, nursing respite care is founded upon the principles of safety and quality in order to facilitate optimal care, and promote child/family² participation in their home and specified community settings (i.e., school). NSS aims to be proactive with providing the correct service and professional at the right time.
 - a. NSS strives to achieve consistent, equitable, comprehensive, coordinated and safe quality care by working collaboratively as an interprofessional team that includes the child, family, doctor/NP/ most responsible provider (MRP), specialists, clinics, community partners, contracted nursing agencies and the Nursing Support Services Team (NSS Team)³.
- 2. As a voluntary and time-limited service (based upon a child's eligibility), the NSS team⁴ believes in a child/family's right to self-determination and choice. The NSS team is committed to transparency and honesty by providing full disclosure about its services and accountabilities. NSS strives to preserve and empower a child/family's dignity and personal control over care within its service model.
- 3. As a provincial program, NSS strives for safe, consistent and equitable care for all children eligible for its services. A child's unique care needs are supported using individualized care plans co-created between the family and the NSS Team.
- 4. A child's eligibility⁵ with NSS is based upon medical care needs that require the knowledge, judgement and skill of a registered nurse for some aspects of their care in the absence of the parent(s)/guardian(s)². All care that nurses provide must be in accordance with their professional and ethical standards of care, and specific to the child's eligibility for NSS. A nurse will provide holistic nursing care during a shift, but will not participate in other non-nursing responsibilities pertaining to the family/home life such as meal making, laundry, medical appointments, groceries, childcare, house cleaning etc.

¹ In this document child refers from birth – 19 years old

² In this document family or parent(s) refers to those individual(s) who have legal rights to the child (i.e. legal guardians).

³ NSS Coordinators, NSS program supports, and/or Health Authority resources, contracted nursing agencies

⁴ Agency partners are those privately contracted by NSS to provide direct in home nursing services to families

⁵ Eligibility is not based upon a child's need for homecare / interventional care support (e.g. wound care, IV therapy, post-operative medical care management and oversight) or care that can be safely provided by non-nursing staff (e.g. washing, dressing)



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- 5. NSS in-home nursing respite and/or in-school⁶ support is intended to provide families scheduled, intermittent rest/sleep/time away from the day-to-day medical care needs of a child with chronic and complex medical conditions. NSS respite is not intended to support a family² to go to work and/or school.
 - a. A family holds the overall responsibility for their child's care.
 - b. Nursing respite will be scheduled in accordance with a child's eligibility for services for those periods that require the knowledge, judgment and skill of a registered nurse for some aspects of their medical care in the absence of parent(s)/guardian(s).
 - c. As a supplementary service to the care of the family, every family needs to have a back-up plan for their child's care/support outside of NSS (e.g., for a staffing sick call).
 - d. NSS is supplemental to a family's care of their child and therefore it is a requirement that the family is trained, prepared, capable and competent to provide all aspects of their child's care in the absence of and independent of nursing support.
 - i. Before a care plan can be put in place, a family needs to be competent⁷ in providing all aspects of care for their child as they are actively involved in participating in and communicating their child's ongoing care plan requirements.
 - ii. NSS offers respite care for medical care needs; nurses can only provide care that a family is also trained and capable of providing related to their child's medical complexity (e.g., administer prescribed medication and oral/tracheal tube suctioning).
 - iii. The NSS team is not responsible for providing education in the home for new care needs and/or equipment for the child.⁷ It is the responsibility of the most responsible care provider such as Pediatrician, Family Physician, Nurse Practitioner and care team that initiated the new care needs and/or equipment to ensure that the family receives the appropriate training and support to care for their child at home/in community.
- 6. NSS respite hours are assigned to contracted nursing agencies and scheduled for time periods consistent with a child's eligibility for services that require medical care so a family can sleep/have time away⁸ from the continued medical surveillance¹⁰ and nursing care⁹ of their child living with medical complexity.
 - a. NSS promotes health and self-care with a focus on family's ability to sleep at night⁸ so that they can better manage their own and their child's needs during the day.
 - b. NSS recognizes that with medically complex children, families typically need to provide awake/overnight care¹⁰ to monitor their child and/or provide interventions, therefore, nighttime respite will be prioritized.

⁶ In-school nursing support is intended for eligible children to actively participate in a curriculum sanctioned and supervised by the Ministry of Education and for those periods when a child receives instruction from an education professional;

⁷ The NSS role could include reinforcing and supporting new aspects of care in the home, but first the family will have had to receive training/education from the most responsible health care professional/service (and validated for that knowledge) (E.g. Suctioning, O2 sat monitoring, tracheostomy and ventilation care etc.)

⁸ Maslow's hierarchy of human needs; Kelty Mental Health Resource Centre - Healthy Sleep Habits

⁹ Knowledge, judgement, skill of a registered nurse

¹⁰ CAPHC National Complex Care Guideline 2018; Cohen, Eval. (March 25, 2021). *Reflections on the emergency of pediatric complex care in Canada*. Paediatrics, Toronto SickKids.



- c. NSS recognizes that medically complex children can be most at risk at night for safety issues¹¹. It is also the time where out-of-hours/after-hours care and resources are less accessible, such as professionals with child specific/specialist knowledge required to advise a parent in need¹².
- d. If applicable, NSS in-school⁶ support hours are allocated and scheduled for the time periods that a child attends school and requires medical care in the school setting; the purpose for school respite being that a child can attend school and focus on learning. In addition, schools are not set up to provide the specialized care required for children living with medical complexity. School hours cannot be transferred to in-home respite support as they are separate; they are in place to support a child to be at school to engage in social interactions and academic development.
- 7. NSS believes in family integrated care¹³ and relies on family partnership and active participation by drawing from and/or building upon¹⁴ family expertise, capacity, strengths, and supporting family leadership in providing care for their child. As medical partners, NSS provides anticipatory, developmentally appropriate health related care and looks to support family empowerment within their normative parenting journey.
 - a. Care plans and support through NSS is intended to facilitate child focused care¹⁵ which is translated into the agency care plan (e.g., independent tracheostomy and vent care), and/or;
 - b. To facilitate care provision (wherever possible) to an established routine and to support those aspects of care that can be safely provided by a non-nurse care providers, and/or;
 - c. To anticipate and facilitate developmentally appropriate and service model transitions in a positive and safe manner (e.g., school, transition to adulthood).
- 8. NSS and contracted nursing agencies are required to provide safe, respectful and appropriate working environments for their staff (guided by professional and legal requirements such as Work Safe BC¹⁶). Using open lines of respectful communication¹⁷, the interprofessional team¹⁸ facilitates timely sharing of information regarding the child's care plan (as per consent).
- 9. Care plans that involve technology support need to have a back-up plan in place in case the technology fails and/or an unexpected event occurs (e.g., power outage).
 - a. Agency nurses will only use technology that has been Health Canada¹⁹ approved and that they have been trained on and validated to use.

¹³ The goal of FICARE is to truly embrace and fully embody the full scope of Patient and Family Centered Care; to facilitate partnership and collaboration. It counts on, values and incorporates the presence and active participation of family in the care of their child. ¹⁴ Drawing upon principals of shared trust and power; CAPHC National Complex Care Guideline 2018

¹¹ E.g. implications of respiratory conditions; normal physiological/anatomical implications when in deep sleep; impact of ongoing sleep deprivation on parent, etc

¹² (Page, Hinton, Harrop & Vincent, 2020). <u>The challenges of caring for children who require complex medical care at home...</u>

¹⁵ This includes a child's transition to independence (as appropriate) founded upon their abilities, using child specific goal planning and integration ¹⁶ <u>CNA-CFNU Joint Statement Practice Environments</u>; <u>CNA-CFNU Joint Statement Workplace Violence & Bullying</u>; <u>Work Safe BC Health and Safety</u>; <u>SafeCare BC</u>

¹⁷ PHSA Respectful Workplace Policy

¹⁸ The interprofessional team includes the child, family, and/or most responsible provider, clinics, community partners, nursing agencies and the Nursing Support Services Team²

¹⁹ Health Canada Medical Devices; Health Canada Approval



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- b. Agency nurses will only use technology and equipment that is functional and working. It is the family's responsibility to maintain their child's equipment as guided by manufacturer service recommendations and agreements.
- c. Agency nurses will complete a safety check on all approved equipment²⁰ at the start of their shift.
- 10. Every child needs to have an emergency/safety²¹ plan that is the responsibility of the contracted nursing agency to put in place with the support/input of the family.
 - a. In the event of an emergency/unanticipated event, nursing as per scope of practice, must be able to make independent judgements around a child's care/interventions as agreed upon in the care plan (wherever possible) until handover to emergency health services/transport and/or a higher level of care (e.g., local hospital) is possible.
- 11. Nursing care and a child's care plan must meet the practice standards as per the BC College of Nurses and Midwives²², contracted nursing agency and/or PHSA clinical policies and procedures, and best practice standards.
 - a. Physician orders direct nurses' care in the home.
 - b. Child, Family, and Community Service Act, duty to report section 13²³.
 - c. A nurse's scope of practice (regulatory and own competencies).
 - d. All relevant employer-based standards, guidelines, procedures, and protocols.
- 12. NSS contracted nursing agencies employ inclusivity in their hiring practices. Nurses are hired based upon their professional qualifications and their availability to support the varied scheduling needs that contracted nursing agencies are accountable for. Each nurse is a registered professional hired to provide safe, competent and ethical practice.

²⁰ Equipment = that which is appropriate to: the medical care being delivered to the child, and for which nurse been both trained & validated for ²¹ Plans need to be in alignment with NSS's respite mandate (i.e. not interventional care) and appropriate to safe care and respective role/scope/function within the community setting (e.g. rescue breathing vs ambu bag breathing)

²² BCCNM

²³ <u>BC Health Regulators</u>, <u>Child, Family & Community Service Act - Child Protection</u>