

Family Assessment for Pediatric Clients Receiving Home Care



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Date: October 2019

Next Review Date: October 2023

Many thanks to the health professionals from the IWK Health Centre, Nova Scotia Health Authority Continuing Care, and VON Canada (Nova Scotia) who reviewed these pediatric home care resources and provided invaluable feedback. Special thanks to my MN supervisor Dr. Joy Maddigan, whose encouragement and wisdom made this project possible.

Disclaimers

This family assessment resource is designed to support current practices for home care in Nova Scotia. Should there be discrepancies, home care professionals should defer to their professional practice guidelines and organizational policies or procedures, and/or discuss questions with their manager.

This resource was developed with the understanding that home care professionals have already received initial and ongoing education in client and family assessment in the home setting; this resource is therefore not a substitute for initial education in client and family assessment.

Instructions

The answers to these questions can be **recorded on approved charting forms**, either paper or electronic. Not every single question may be suitable for every client and family situation; **use your professional judgement** regarding what to ask and in what order.

For all pediatric clients (age 0 to 18 years), home care professionals should complete sections A and B.

Section C is **strongly recommended** for all clients and families to assess family functioning.

Sections D and E are optional, because they are dependent on individual client and family situations.

Pediatric Family Assessment Tips

- ❖ Every family is different, and the family is who the family says they are.
- ❖ The family is the pediatric client's context - to understand client needs you have to understand the family.
- ❖ Even though most pediatric clients are not old enough to sign an official consent, most are able to give their assent. This means the client can give developmentally-appropriate agreement and participation.
- ❖ Ensuring participation of pediatric clients is an important part of pediatric care, as long as their developmental level permits, and as long as they are not harmed by participating (this would be rare).
- ❖ Don't default to asking the parent/guardian all the questions.
- ❖ Ask the client questions directly, according to their developmental level. e.g. Ask a young child which toys they like, ask a school-age child what it was like when they were in the hospital, ask a teenager about their chronic illness, etc.
- ❖ It's okay to allow the client and family to lead the conversation to where their concerns are, even if it doesn't fit in the general assessment categories.
- ❖ Show empathy and understanding for the family's situation wherever you can, and validate the family's emotions and struggles. This will help build trust and a professional relationship.
- ❖ Show respect and humility in domains where families have expert knowledge.
- ❖ Acknowledge and highlight areas of family resilience and strength.
- ❖ Be genuine and non-judgmental as you build understanding of the family's situation.

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Family Assessment for Pediatric Clients

Part A: General Information

- ❖ Who is the source of information for the assessment? The client, parent/guardian, or someone else?
- ❖ What language(s) are being used? Is interpretation required?
- ❖ Who is/are the substitute decision maker(s)?
- ❖ What is the client's level of involvement in health discussions?
- ❖ What is the client's current understanding of their health issues?
- ❖ Who are the family members living in the home?
- ❖ Are there siblings? What are their ages? Do any siblings have health issues?
- ❖ Is there any immediate family living outside the home?
- ❖ What are the parents' means of employment?
- ❖ Does the client have health insurance coverage?
- ❖ Does client live between multiple households? Are there any special custody arrangements?
- ❖ Does the client have caregivers other than their immediate family?
- ❖ Does the client and family have support from extended family or the community?
- ❖ Who are the client's main friends/social supports?
- ❖ Who are the family's main friends/social supports?
- ❖ Who are the client's and family's health care support? The family physician or nurse practitioner, community pediatrician, specialty teams, or others?
- ❖ Does the client and family have cultural, religious, or spiritual supports?
- ❖ Does the client attend daycare, preschool, or school? Does the client require any special educational supports? What is the daycare or school schedule?
- ❖ What are the client's play preferences, interests, and/or hobbies?
- ❖ Does the client have any employment? (For older pediatric clients).

Part B: Client Health and Illness – Impact on the Family

- ❖ What are the parent's concerns about the client's health?
- ❖ What are the client's concerns about their own health?
- ❖ What are the parent's concerns/goals for home care?
- ❖ What are the client's concerns/goals for home care?
- ❖ What is the client's reaction to medical procedures? Are there ways to distract/help with procedures?
- ❖ What is the impact of the illness on the client – emotions, usual routines, school, etc.
- ❖ What is the impact of the illness on the family – emotional state, family routines, etc.

Part C: Family Functioning

➔ This section is used to assess general family functioning, particularly when stressors are present.

- ❖ What is the client's and/or parent's sense of the family's well-being in the midst of the client's illness?
- ❖ What are the current family stressors in addition to the client's illness – Financial? Employment? Cultural? Religious/Spiritual? Physical health? Mental/Emotional health? Needing additional supports?
- ❖ Family strengths: Members generally get along, members help out, open communication, joint problem solving, accepting of others, etc.
- ❖ Family limitations: Members don't get along, some members bear most of burdens/responsibilities, hard to communicate in certain situations, challenges with problem solving, not accepting of certain family, etc.

*If red flags are present, the family as well as the client are at risk for poor family functioning. Consider supports available within your role, and refer to part E for additional family resources.

Part D: Family Considerations for Special Populations

Clients with Chronic Illness

➔ This section pertains to pediatric clients who have simpler chronic illnesses, (i.e. diabetes, cystic fibrosis, Crohn's disease) as opposed to children and youth with medical complexity, noted in the next section.

- ❖ How does the chronic illness affect the client – positively and/or negatively?
- ❖ How does the chronic illness affect the family – positively and/or negatively?
- ❖ Who has caregiving roles related to the chronic illness? How do the caregivers take breaks?
- ❖ How does the family cope with the demands of the chronic illness?
- ❖ Who/what is a support for the family in living with chronic illness – Help with caregiving? Financial support? Personal or emotional support?

*Coping patterns that are atypical may actually be functional in families with a child who has a chronic illness. i.e. A strict or inflexible schedule may be a functional way to manage chronic illness in a family. If a coping technique or pattern works well for the client and family even though it's not typical, it may be acceptable.

Clients with Medical Complexity

➔ A child or youth with medical complexity (CYMC) has one or more health conditions that affect multiple body systems; has functional limitations that often include technological dependence; has high service use across health and other sectors; and their family has high self-identified needs. When in doubt, it's better to consider a client as medically complex.

- ❖ Does the client have an IWK complex care plan? Is a copy on file?
- ❖ Does the client have any advance directives or DNR instructions aside from the complex care plan? Are the directives on file?
- ❖ Does the client have an EHS special patient protocol? What is the patient protocol number?
- ❖ How does having complex care needs affect the client – positively and/or negatively?
- ❖ How does having a child or youth with complex care needs affect the family – positively and/or negatively?
- ❖ Who has caregiving roles for the client? How do the caregivers take breaks?
- ❖ What are the family's coping mechanisms related to the client's care?
- ❖ Who/what is a support for the family as they care for the client – Help with caregiving? Financial support? Personal or emotional support? Disability support program from DCS? Support from certain health professionals or health teams?
- ❖ Ask the primary caregiver to rank their stress level on a scale of 0 to 10 – 0 is no stress, and 10 is the most stress they can handle. Is this their typical stress level? Has it increased/decreased lately?

*Families of CYMC are at higher risk for caregiver fatigue and caregiver burnout. These caregiving risks are linked to chronic anxiety or worry about the child's health, grieving the loss of a "normal" life for the child, living with long-term uncertainty, living with high vigilance, chronic sleep deprivation, and other factors.

Clients Receiving Palliative Care

➔ In pediatrics, clients receiving palliative care may or may not be at end-of-life. In most cases, a child who has a life-threatening or life-limiting illness will be followed by palliative care, whether they are expected to live a short time (weeks to months) or a long time (years to decades). When palliative care is involved, the focus is on optimizing the client's and family's quality of life no matter what the stage of the client's illness.

- ❖ Does the client have an IWK complex care plan? Is a copy on file?

- ❖ Does the client have any advance directives or DNR instructions aside from the complex care plan? Are the directives on file?
- ❖ Does the client have an EHS special patient protocol? What is the patient protocol number?
- ❖ What are the client's most important priorities for quality of life?
- ❖ What are the family's most important priorities for quality of life?
- ❖ Are there particular symptom management challenges for the patient? If so, what are the best ways to manage these symptoms?
- ❖ Are there certain health professionals the family contacts to help with symptom management? If yes, note their contact information.

Clients at End-Of-Life

- ⇒ This section is for clients who are actively dying, whether death is expected in months, weeks, or days. Wishes and plans for end-of-life may change as time goes on, so this assessment may be performed multiple times if needed.
- ❖ What are the client's hopes, fears, and preferences for end of life?
 - ❖ What are the family's hopes, fears, and preferences for end of life?
 - ❖ Where does the family hope death will occur? Home, hospice, hospital, other?
 - ❖ What supports may be needed for siblings, other close family members, or friends?
 - ❖ Are there any plans for symptom management and rapid escalation of care needs at end of life? If yes, note relevant information.
 - ❖ Are there certain health professionals to contact for help with symptom management and rapid escalation of care needs? If yes, note their contact information, including the hours these professionals are available, if they are not available 24/7.
 - ❖ Are there certain family members or friends who should be called if death is imminent? If yes, note their contact information.
 - ❖ Does the family have any special considerations or preferences for the time just after death? e.g. Being alone with the client, having only particular people with the client, memory making, cultural, religious, or spiritual rituals, etc.
 - ❖ What are the family's preferences for bereavement follow-up and support from home care professionals? Would the family be open to receiving a card or a phone call after the client's death, for example?

*The IWK's Pediatric Advanced Care Team (PACT), which provides palliative care services, as well as palliative care teams in local communities, are excellent resources for home care professionals. These teams can provide advice on how to support clients and families, and they can suggest resources for siblings and friends during the end-of-life and bereavement phases. If helpful, these teams are available for self-care and debriefing sessions.

*It is very important for care providers who were involved with the client and family to engage in meaningful follow-up during the bereavement period. Even a phone call or card can help families feel that they and the client were not forgotten after the client's death, and that the client is remembered by care providers.

Part E: Family Support Resources

1. Families can visit their primary care provider (family doctor or nurse practitioner) to ask for guidance. If they need to find a primary care provider, they should visit the Family Practice Registry website (<https://needafamilypractice.nshealth.ca/>) or call 811.
2. Families could access an Employee Assistance Program (EAP). EAPs are free services available to many parents and families from the parent's employer. EAPs include counseling and support services available in person, online, or by phone. Parents can check with their employer to see if they have an EAP.
3. Families with private insurance may be eligible for counseling services. Families should check and see what counseling coverage they have. For social worker counseling, visit the Nova Scotia College of Social Work private practice listing (<https://onlineservice.nscsw.org/webs/nscsw/>) to find a social worker. For psychologist counseling, visit the Psychology Association of Nova Scotia website (<https://apns.ca/>) to find a psychologist.
4. The Department of Community Services (<https://www.novascotia.ca/coms/>) provides a variety of community-based supports for individuals and families, such as the Disability Support Program for children and adults, Income and Employment Assistance, and Child, Youth, and Family supports. One resource made in partnership with Public Health is the "Loving Care" series of free guides on parenting (<https://novascotia.ca/dhw/lovingcare>).
5. Public Health is focused on promoting good health and preventing disease in the home and community setting. Their healthy development resources (<https://novascotia.ca/dhw/healthy-development/>) include support during pregnancy, breastfeeding, early childhood, and more. Their healthy community resources (<https://novascotia.ca/dhw/healthy-communities/>) include support for healthy eating, injury prevention, and more. Families may visit a public health office (<http://www.nshealth.ca/public-health-offices>), public health's family resource centers (<https://www.cdha.nshealth.ca/public-health/family-resource-centres>), or the Public Health main website (<https://novascotia.ca/dhw/publichealth/>) for more information.
6. Caregivers Nova Scotia (<https://www.caregiversns.org/>) is an organization that helps anyone who is a caregiver for someone with special health needs. Their website has a variety of resources such as self-care ideas for caregivers, a respite services directory, and more.
7. The Nova Scotia Respite Guide (<https://novascotia.ca/coms/disabilities/documents/Nova-Scotia-Respite-Guide-for-Caregivers-of-Children-and-Adults-with-Disabilities.pdf>) is designed to help Nova Scotia caregivers understand what respite is, how to find respite, and how to plan for respite in their day to day life.
8. Call/text 211 or visit the website (<http://ns.211.ca/>) to find community programs across Nova Scotia.
9. Community Health Teams (<http://nshealth.ca/service-details/Community%20Health%20Teams>) offer free health and wellness programs in the Halifax region. These programs are led by health professionals from the NS Health Authority and the IWK Health Centre on topics such as making the most of your food budget, how to increase your activity level, dealing with stress, parenting a toddler, and more.
10. Call 811 for non-emergency health advice from a registered nurse in Nova Scotia.
11. Families experiencing a mental health crisis can call 902-429-8167 for support. For mental health emergencies, call 911 or go to your nearest Emergency Department.

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