

Eating Disorders

A guide for caregivers of people with an eating disorder



**Ontario
Health**

Ontario Health is committed to improving the quality of health care in the province in partnership with patients, caregivers, health care professionals, and other organizations.

To do that, Ontario Health develops quality standards. These are documents that outline what high-quality care looks like for conditions or processes where there are large differences in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. These quality standards set out important steps to improve care. They are based on current evidence and input from an expert committee that includes patients, caregivers, health care professionals, and researchers.

The care described in the caregiver guide is intended to outline the best way to provide care for people with an eating disorder in Ontario. But this may not always reflect how care is currently delivered or the services that are available right now. There are challenges in the health care system that need to be addressed, and this can be frustrating for patients and their family and caregivers. The goal of this document is to help you understand the type of care people with an eating disorder should be receiving to help them get healthy and stay healthy.

This caregiver guide accompanies the [quality standard on eating disorders](#). It outlines the top nine areas where providers can take steps to improve care for people with an eating disorder. The caregiver guide and the [patient guide](#) also include suggestions on what to discuss with health care providers, as well as links to helpful resources.

Caregivers take on many different roles in the care for people with an eating disorder. If the person you are caring for is under 18 years old, you may be very involved in their care and treatment. Caregiver involvement depends on the situation and can change over time.

Is the person you are caring for in crisis? If they need immediate help, please do one of the following:

Go to the nearest hospital or emergency room

Call 9-1-1

Call a helpline:

- [Health811](#)—24/7 health advice (call 811 or TTY: 1-866-797-0007; available in English and French)
- [Ontario Network of Sexual Assault/Domestic Violence Treatment Centres](#)—for community services and resources about sexual assault and domestic violence (available in English and French)
- [Kids Help Phone](#)—24/7 e-mental health service for young people (text CONNECT to 686868 or call 1-800-668-6868)
- [ConnexOntario](#)—for help for mental health and addictions (1-866-531-2600)
- [Distress and Crisis Ontario](#)—to find a crisis centre near you
- [Hope for Wellness Help Line](#)—24/7 help for Indigenous peoples across Canada (available in Cree, Ojibway, and Inuktitut upon request)
- [Trans Lifeline](#)—a peer support phone service run by trans people for trans and questioning peers (available in English and Spanish)

Below is a summary of the top nine areas to improve care for people with an eating disorder.



Quality Statement 1: Comprehensive Assessment

What the standard says

People with signs and symptoms of an eating disorder have timely access to comprehensive mental and physical health assessments. The assessment is used to determine whether they have a specific eating disorder, the severity of their symptoms, the degree of impairment, and whether they have any comorbid conditions, and to establish a plan of care.

What this means for you

- Health care providers should ask the person you are caring for (and you, depending on the circumstances) questions about their thoughts, feelings, behaviours, and physical health.
- They will do this to find out whether the person has an eating disorder, and to make a plan for their care as soon as possible.

If appropriate, the health care team of the person you are caring for may involve you in their care. Some people with an eating disorder may not want treatment. They may need to be encouraged by a caregiver to get the most appropriate care. If you want to, schedule time with the care team to discuss any questions or concerns you may have.

Consider:

- Sharing your knowledge and expertise about the person's condition and needs
- Asking questions you may have about the care
- Asking about available support groups or resources for caregivers
- Letting the health care team know if you need help



Quality Statement 2: Level of Care

What the standard says

People with an eating disorder receive the most appropriate level of care, which takes into consideration their needs, goals, and experience with previous treatment.

What this means for you

- Health care providers should offer the treatment option that has the best chance of helping the person you are caring for and is the least disruptive to their life (for example, is as close to home as possible).
- If the person's symptoms don't improve with this treatment, their health care providers should offer the next most appropriate treatment option for them. This should be done in a coordinated way.

Levels of care for eating disorder treatments include:

- Self-directed interventions: activities the person with the eating disorder can do on their own to address their condition (e.g., using books, manuals, online resources)
- Group therapy: therapy provided to a small group of people with similar eating disordered behaviours
- Individual therapy: therapy provided by a health care professional in one-on-one sessions
- Outpatient treatment: shorter visits at a clinic or hospital
- Day treatment: longer visits at a hospital or other facility that does not require overnight stay
- Live-in treatment (formerly referred to as residential treatment): longer-term 24-hour care that requires overnight stay at a facility that is not an acute care hospital
- Inpatient treatment: overnight care at a hospital, which may include *medical stabilization* (more intensive treatment to help the body recover)



Quality Statement 3: Transition From Youth to Adult Health Care Services

What the standard says

Young people with an eating disorder who will transition out of youth-oriented services to adult-oriented services receive transitional care that focuses on continuity and helping the young person develop independence.

What this means for you

- If the person you are caring for is moving from care for young people to care for adults, they should receive support that helps them become more independent.
- The person with an eating disorder should be involved in their own care, and there should not be any interruptions to their treatment.
- Depending on the circumstances, you may also be involved in their care throughout this transition.

Transitions From Youth to Adult Health Care Service

Ontario Health has also developed a quality standard on [Transitions From Youth to Adult Health Care Services](#) that outlines key improvement areas for young people undergoing this transition. It includes [Resources for Young People and Their Caregivers](#) with websites, apps, transition plans, and other resources to help support successful transitions to adult health care services.



Quality Statement 4: Psychotherapy

What the standard says

People with an eating disorder receive timely access to evidence-based psychotherapy that considers their individual needs and preferences.

What this means for you

The person you are caring for should be offered a type of treatment called psychotherapy. It should be available as soon as possible after their assessment.

Psychotherapy can:

- Help the person you are caring for establish regular eating patterns
- Provide education about eating disorders and how to get better
- Improve their thoughts and feelings about eating and their body shape and weight

If the person you are caring for agrees to psychotherapy, they should not need to wait too long to start treatment.

Psychotherapies for eating disorders may include but are not limited to:

- Family-based treatment (single- or multi-family therapy)
- Cognitive behavioural therapy (CBT)
- Interpersonal psychotherapy

More information on types of psychotherapy can be found at the [National Eating Disorder Information Centre's website](#). Ask your health care provider if you have any questions about any of these treatments.



Quality Statement 5: Monitoring and Medical Stabilization

What the standard says

People with an eating disorder receive ongoing medical monitoring to prevent and address adverse events and complications. They are offered acute medical stabilization when indicated.

What this means for you

- Health care providers of the person you are caring for should check in with them regularly to see how they are feeling (physically and emotionally).
- Health care providers may also suggest medical stabilization to manage the person's eating disorder. This may involve being admitted to a hospital until they are physically healthier.
- The health care team should check on the person you are caring for regularly while they are in the hospital.



Quality Statement 6: Support for Family and Caregivers

What the standard says

Families and caregivers of people with an eating disorder are offered resources, structured support, and education in a way that meets their needs.

What this means for you

If you are involved in the care of a person with an eating disorder, their health care providers should ask you how you are doing, and offer you support if you want it. Support could include:

- Offering you information about the eating disorder, in the language of your choice, if possible.
- Helping you find a support group where you can talk with other people who are supporting a person with an eating disorder.
- Guided and unguided self-help interventions for family and caregivers of people with an eating disorder based on cognitive behavioural therapy techniques.

You might feel overwhelmed sometimes while caring for a person with an eating disorder. Make sure you ask for help if you don't understand any part of the disorder or treatment, or if you need extra support for yourself.



Quality Statement 7: Physical, Mental Health, and Addiction Comorbidities

What the standard says

People with an eating disorder who have physical, mental health, or addiction comorbidities are offered treatment for their eating disorder and other conditions as part of a comprehensive plan of care.

What this means for you

- If the person you are caring for has other physical, mental health, or addiction conditions, their health care providers should offer them treatment for both their eating disorder and any other condition they have.
- If the health care providers are not able to treat the other conditions, they should connect the person with a care provider who can, and work with that provider.
- Health care providers should involve the person you are caring for (and you, depending on the circumstances) in decisions about their care.



Quality Statement 8: Promoting Equity

What the standard says

People with an eating disorder experience care from health care providers and a health care system that uses an anti-racist, anti-discrimination, anti-stigma, and anti-oppressive approach. Health care providers promote a culture that is compassionate, trauma informed, unbiased, and respectful of people's diversity. They build trust with people with an eating disorder and their families and caregivers, work to remove barriers to accessing care, and provide care equitably.

What this means for you

- The person you are caring for should feel like they are being treated with respect, dignity, and compassion by their health care providers.
- They should receive care in a manner that respects their identity and is free from bias.
- Care providers should work with the person you are caring for to understand their eating disorder and how treatment is affected by their unique identity. They should be respectful of, and attentive to, cultural differences (among other things).
- The person you are caring for should be able to get high-quality health care when they need it, no matter where they go (for example, at your doctor's office or at the hospital).

Trauma-informed care:

Trauma-informed care is health care that reflects an understanding of trauma and the impact that traumatic experiences can have on people. This approach does not necessarily address the trauma directly. Rather, the approach acknowledges that a person may have experienced a previous traumatic event that may contribute to their current health concerns. It emphasizes understanding, respecting, and responding to the effects of trauma.



Quality Statement 9: Care for People Who Are Not Receiving Active Treatment

What the standard says

People with an eating disorder who are not receiving active treatment are offered medical monitoring, support, and follow-up that meets their needs and preferences.

What this means for you

The person you are caring for may not be receiving active treatment for their eating disorder for any of the following reasons:

- They are waiting for treatment
- They have finished treatment
- Treatment hasn't helped in the past
- They don't want it or aren't ready for treatment

If this is the case, health care providers should continue to offer other support that meets the person's needs and preferences and connect them (and you, depending on the circumstances) with other available resources.

Suggestions on what to discuss with health care providers

Ask the care team:

- How can I identify early signs of eating disorder behaviours or symptoms?
- What treatment options are available to the person I'm caring for, and how can they get quick access to treatment?
- How do I help the person I'm caring for keep up with their treatment?
- How will I know if I need to seek help? When should I take them to the hospital?
- What might their recovery look like?
- Is it possible to fully recover from an eating disorder?
- What community supports are available to me and the person I'm caring for?

Share with the care team:

- If you notice that the person you are caring for is showing any signs of eating disorder behaviours or symptoms
- How the person is feeling overall, and what it's like for them to manage their eating disorder behaviours or symptoms
- If there are things that make it difficult for them to continue treatment, such as cost or long waitlists
- If you or the person you are caring for is feeling overwhelmed and needs extra support
- If the person you are caring for is having thoughts of hurting themselves or others
- The type of information and support you both want from your health care team
- Any experience they have had with any previous eating disorder treatment
- If either of you doesn't understand why they are receiving a certain treatment or how it will help
- What gives the person you are caring for hope or brings them joy
- Any questions or concerns you have about their care or treatment



Learn more

The [National Eating Disorder Information Centre](#) (NEDIC) provides information, resources, referrals, and support to people living with an eating disorder, as well as parents, caregivers, friends, educators, and health care professionals. Offerings include:

- A toll-free helpline (1-866-633-4220) and live chat offering support, answers, and assistance in finding eating disorder treatment
- An interactive [Find a Provider](#) tool to help people find eating disorder treatment based on their postal code, virtual or in-person care preference, and insurance coverage
- A directory of [eating disorder community groups](#) by province and an overview of their services
- Resources, tips, tools, and general information for [individuals](#), [children](#), [youth](#), and [adults](#) with an eating disorder, and their [caregivers](#)
- [Self-Advocacy: Taking Action to Meet Your Needs](#) is a resource from NEDIC that addresses additional issues that individuals with an eating disorder may experience during their recovery journey if they identify as two-spirit, lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, and additional sexual orientations and gender identities (2SLGBTQIA+)

The [National Initiative for Eating Disorders](#) (NIED) supports people by providing educational, informational, and other recovery-oriented resources related to the prevention and treatment of eating disorders and related mental illnesses in Canada. Their [Eating Disorders Safety, Crisis Readiness and Other Essential Information for Caregivers](#) is a helpful tool for caregivers.

[First 30 Days – Families Empowered And Supporting Treatment for Eating Disorders \(F.E.A.S.T.\)](#) is a free education program that aims to help parents be informed and empowered caregivers. (Available in 12 languages.)

[Canped.ca's Understanding Eating Disorders in Adolescents](#) is a free online education tool for parents and caregivers. It includes six modules containing education videos.

[Youth Wellness Hubs](#) are "one-stop-shops" offering mental health, substance use, primary care, vocational, housing, and other support services to young people aged 12 to 25 in a youth-friendly space. (Available in English and French.)

Need more information?

If you have any questions or feedback about this guide, please contact us at QualityStandards@OntarioHealth.ca or 1-877-280-8538 (TTY: 1-800-855-0511).