# **SELF-ADVOCACY:**

Taking Action to Meet Your Needs

Every person who struggles with an eating disorder deserves compassionate, non-judgmental, affirming care from the support options they choose to access. Some, however, might not have this experience. As there is plenty of work to be done to better educate and train care providers to be eating disorder-sensitive so they avoid causing harm, 2SLGBTQ+ communities in particular often have to **self-advocate**. This process often includes:

- An understanding that every person is deserving of support
- Reflection on what their goals and boundaries are
- Communicating these goals and boundaries to the people who are caring for them



### Thinking about recovery

Eating disorders are notoriously difficult to resolve. Sometimes healthcare professionals and loved ones blame a person for their challenges throughout recovery. It should be expected that people might struggle within a world that upholds a narrow range of body types, gender presentations, and appearances as 'normal'. When recovery is defined by weight-related outcomes and normalization of eating habits, people are pushed to get back to 'normal'. This definition ignores that their distress around bodies and food may have originated from rigid expectations of what it means to have a 'normal' gendered body. It ignores the fact that some people will still be subject to body-based harassment, discrimination, and shaming even after they have 'recovered'. It ignores narratives that can make recovery difficult, like 'born-in-the-wrong-body' stories that can make disordered eating seem like a rational behaviour to 'correct' a body.

There is space for all the complicated and messy feelings we have around gender, bodies, and food. Recovery doesn't mean that you will never feel pressure to control your diet, weight, or shape ever again, especially because so much of that pressure comes from outside. Recovery can look like loving your body, appreciating everything it can do, and still wishing it were different. For trans people, recovery can look like getting the transition you want, even though some parts of transitioning may not be exactly what you expected or desired. It is okay if you're not ready to take another step forward and to ask people to meet you where you are instead.

When we let go of 'normal', recovery can mean living with and enjoying the brilliance of our bodies exactly as they are. A recovery that moves towards ordinary and familiar allows us to be creative in how we promote body love, acceptance, and satisfaction. It allows for creativity in how we resolve the distress we feel around food and bodies. Recovery is about much more than just an absence of disordered eating. It's about a reconnection with the self and with others. Perhaps the most important thing about recovery is that it very rarely happens alone. We heal best when we feel safe, connected, understood, and valued. Family, friends, and partners who love, support, and validate us are so important in the journey to finding peace and self-love. There is a whole community on this road with you.

"Don't mistake me: I don't mean we need to find normal and make it our own. Normal — that center against which every one of us is judged and compared: in truth I want us to smash it to smithereens. And in its place, celebrate our irrevocable different bodies, our queerness, our crip lives, telling stories and creating for ourselves an abiding sense of the ordinary and the familiar."

- Eli Clare

### **Taking a Harm Reduction** Approach to Goal-Setting

Harm reduction is an approach focused on reducing the harmful effects of some behaviours, recognizing that abstaining from or eliminating those behaviours entirely might not be a realistic or desirable goal, especially in the short-term. It accepts that the behaviours, for better or worse, are a part of the person's experience and often occur for complex reasons that are not easy to fix. Harm reduction acknowledges that there are often safer ways a person can engage in a certain behaviour, and involves non-judgmental planning around the behaviours to limit the danger to a person's health and improve their quality of life. Harm reduction approaches have been successfully used to optimize the safety of people with HIV/AIDS, and people who engage in drug use and sex work, in both community and professional settings. (adapted from the National Harm Reduction Coalition)

Some behaviours associated with disordered eating to which you might want to apply a harm reduction approach include the restriction of calories or certain types of foods (e.g., dieting, non-religious/spiritual fasting), over-exercising despite pain, and the misuse of substances like laxatives, diet pills, or performance- or muscle-enhancing supplements.

The exact way that harm reduction can be applied to your life is personal; you have the power to choose how you will practice. Here are some proactive steps that might be helpful to think about:



Know when to get help: What are the warning signs when you are beginning to struggle? Think about specific thoughts, feelings, or behaviours that come up.



Coping skills: What can you do, by yourself, to manage the concern? What obstacles might show up when you try to use these skills?



**Social support:** If you're finding it difficult to deal with your distress alone, who is in your web of support? If you have trouble putting one together, you can always contact the NEDIC helpline to get some ideas! Think about aligning appropriate supports with your level of distress (e.g., calling a crisis line when you're at an 8/10; calling a friend when you're at a 3/10). You know yourself best.

Here's an example of how to set some goals around reducing the harm of over-exercising behaviours that one might experience when they're struggling with disordered eating. These plans are best created with a support team (loved ones, peer support, professional support, etc.) to help you catch factors that you might miss.

Realistic Harm Reduction Targets	Unrealistic Harm Reduction Targets
Concrete and specific – "Change running habits from daily to four times a week"	Vague – "Change running habits"
Doable – "Only run after eating a meal"	Too big or difficult – "Stop running every day"
Quickly and easily monitored – "After my run, I'll ask myself: do I feel pain that's higher than 5/10? Do I feel dizzy or faint? If yes, I know I need to adjust more."	Ambiguous or lacking guidelines – "Decide if this plan is working based on how I feel"
Prioritized – Immediate targets focus on minimizing risk from behaviour (e.g. running without corresponding energy intake); long-term targets focus on increasing comfort for the person (a different relationship with movement and eating)	Everything or nothing is urgent – "I have a big list of things to do next time I plan on running and I'll try them all"
Done with support or a plan — "I'll talk about how I'm feeling in my support group next week"; "I know there's a part of me that would've wanted to exercise more so I'll plan to soothe those emotions by journalling when I get home."	Done in isolation or without a plan for caring for yourself after engaging in the behaviour - "When I get home, I'll move onto my next task"

(Tomkins, 2014)

### **Finding Support**

It can be hard to advocate for yourself at times and communicating your needs does not always mean that they will be respected. This is one of the reasons why it's important to have supportive people in your corner. This will look different for everyone, and might include family support, a trusted friend, 2SLGBTQ+ communities and spaces, or a mentor. Remember many people are struggling with similar experiences as you, and there are resources that might be able to help online, or in some cases, in your local community.

## Getting help earlier from a supportive community can reduce harm.



## What makes it hard for people to receive inclusive medical care and treatment?

Treatments for eating disorders can be inadequate for a lot of reasons. Here's a short list:

- People whose bodies and eating habits don't match up specific criteria can face access barriers. Fat people often aren't able to access treatment because their eating disorder isn't seen as a risk, and their disordered behaviours may even be framed as beneficial if it means they are losing weight.
- Fatphobia, transphobia, homophobia, racism, and other problematic attitudes exist throughout the healthcare system, which can cause marginalized patients to experience harm when they access medically based treatments.

- Some professionals misunderstand the nature of our feelings towards our bodies. They may know little about eating disorders, and even less about 2SLGBTQ+ identities.
- A diagnosis of any kind is meant to set apart what's abnormal from a defined 'normal'. Many people have difficulties with their body image, food, and eating, but aren't diagnosed.
- Finally, eating disorders can be treated as an individual, biological problem, when in reality they have as much to do with a person's social environment as they do with their body.

#### What can you do if you don't feel supported?

- Communicate what your needs are, what your goals are, and what safeguards you need to be put in place.
   You can write and plan these ahead of time so you feel prepared to go into an appointment with a primary care provider, psychologist, therapist, or dietitian.
- Determine if your care provider is 2SLGBTQ+ friendly.
  Ask (if you feel it is safe to do) whether they have experience working with 2SLGBTQ+ folks. You deserve gender- and identity-affirming care.
- When possible, it can be helpful to talk to your closest or most supportive people first, and work with them to develop a plan for conversations you anticipate being more difficult (i.e. with parents or health care providers).
- Trust yourself when it comes to your experience with healthcare providers – only you know if it feels like a good relationship, and what might be a good experience for some might not be acceptable for others.



For information, support, resources, and referrals, chat with us online at nedic.ca or toll-free 1-866-NEDIC-20 (416-340-4156 GTA).

To learn more about eating disorders in the 2SLGBTQ+ community, visit: nedic.ca/2slgbtq