

# Stigma, identity and living with obesity

A patient perspective

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# Introduction

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Obesity is defined as a disease.<sup>1-3</sup> More precisely, it is considered a “chronic relapsing disease”. This means that it is treatable but, like many other chronic diseases, the treatments are lifelong.<sup>4</sup> Obesity is therefore a permanent part of the person’s life, always there, always needing to be dealt with.

Traditionally, the solution to obesity has been seen as weight loss, usually by constant and extreme dieting. But modern research shows that extreme dieting is seldom a way forward.<sup>5</sup> The body resists quick and dramatic weight loss, which instead often leads to more weight gain. Therefore scientists and clinical experts do not recommend “quick-fix” solutions.<sup>4</sup> Instead, they stress the need to make lifelong, healthy and enjoyable changes that will improve overall quality of life.

The success of obesity management is thus not measured just in weight loss goals but needs to be based on a person’s health goals and personal needs. For many individuals, being healthier, feeling happier or being able to travel on airplanes may be more important or relevant.

Obesity management also involves addressing weight bias or stigma.<sup>6</sup> Individuals with obesity face pervasive weight bias from family members, friends, health professionals, teachers and employers.<sup>7</sup> Experiencing weight bias has personal and social consequences.<sup>8</sup>

This booklet is about self-management of the physical, mental and social consequences of obesity, and about regaining control of one’s own health and life. It is written from the perspective of persons who have obesity but we hope it will also be useful for health professionals and others. It is based on peer-reviewed research, complemented by professional expertise and the authors’ lived experiences.

We describe ways that you as a person with obesity can cope with living with a chronic disease. We introduce the concept of “personal recovery” and discuss personal identity, self-confidence and other issues involved in living with obesity.

# What is weight stigma?

Weight stigma, also referred to as weight bias, is defined as negative attitudes toward, and beliefs about, others because of their weight. It refers to social stereotypes and misconceptions about people with obesity. Weight-based discrimination occurs when we treat individuals unfairly because of their weight.<sup>9</sup>

The word stigma comes from ancient Greek culture. Physical markings on a person were used to define his position in society, such as a criminal or disabled or, if a slave, to establish ownership.

## Weight stigma and appearance

There are four classic traits that indicate social status – gender, class, race and age. To these we can add size and weight. Gender, race, age and size are all immediately visible at the very first meeting, sometimes class as well, solely by the presence of the person's body. How you are categorized by each observer influences your social status.

## Goffman's three types of stigma

In his ground-breaking book "Stigma", Erving Goffman referred to three major types of stigma:

- Physical deformity, which includes body size;
- Flaws of character, and;
- Genetic connection to race, nation, religion.

Weight stigma exists in our culture and influences our lives — all the time! When we meet a person with obesity and perceive the person's large body size, one or more of Goffman's three types of stigma tend to become activated, whether we are aware of it or not. Just by living in today's society, we are all subject to weight stigma.<sup>10</sup>

## Consequences of weight stigma

There is extensive research on the consequences of weight stigma.<sup>11</sup> Health professionals often have biased attitudes towards patients with obesity. This can lead to their spending less time with patients living with obesity, for example. Stigma impacts health system policies, limiting access to evidence-based obesity management and rehabilitation support.<sup>12</sup>

For you as a person with obesity, weight stigma can also have negative effects on friends and family, in schools and other educational settings, when seeking employment or housing. We explore these effects below in the section "The social implications of obesity".

## Weight stigma exists everywhere and affects everyone

Social stereotypes about thinness and overweight combined with risk of weight gain due to various factors can stir up discomfort and sometimes even hostility that in turn might openly be directed towards individuals who have overweight. Social pressures to have a thin body continue to intensify and equate thinness with "happiness" and "success". Consider, for example, how there is a multi-billion-dollar weight loss industry promoting unrealistic weight loss and promising a happier self and increased life opportunities and success.<sup>13</sup>





## Internalized weight bias

As a person with obesity, no matter where you go or who you meet, obesity stereotypes and misconceptions are always there, sometimes openly, sometimes in the background. This recurring confrontation with stigma in your environment can lead to negative self-perception and “internalised weight bias”. You begin to believe that you are lazy or have a weak character, are unattractive, or whatever the stigma is telling you.<sup>6,14</sup> This results in:

- Blame and shame
- Pressure from public opinion
- Stress
- Vulnerability

## Responses to internalized weight bias

Internalised weight stigma can lead to a variety of responses:

### Emotional

- Feelings of not “fitting in” and not being “normal”;
- Feelings of not being accepted and respected as a human being;
- Negative thoughts and self-talk;
- Feelings of shame and blame;
- Vulnerability, which can cause stress, anxiety, depression, suicidal thoughts and eating disorders.

### Behavioural

- Feeling helpless and unable to engage in health promoting behaviours;
- Unhealthy coping methods such as binge eating or reduced physical activity;
- Suicidal acts.

### Physiological

- Increased chronic stress can activate physiological mechanisms that in turn can lead to increased weight.

### Social

- Avoidance of interactions with health professionals for fear of blame and shame;
- Fear of being excluded.

# Social implications of obesity

Obesity occurs in a social context and causes inequalities. Aspects of our physical health have consequences for our social situations, which means that our social situations affect our health and, for persons with obesity, can lead to more weight gain.<sup>15</sup>

A combination of social factors can lead to a downward spiral in which your quality of life becomes progressively worse:



## Family life

Many people with obesity have experienced stigma in the intimacy of their own family. Teasing by friends and family is common and often goes uncontested.



## Social network

The person with obesity might not be considered attractive. Normal relationships may be hindered if other people fear being tainted by social contacts. This can restrict the choice of partner and limit the number of close friends.



## Education

Many children and young persons are bullied in school, sometimes brutally, because of their weight. Weight stigma can limit admission to college or university, especially if an interview is required.



## Employment

Stereotyping persons with obesity as lazy and lacking discipline fuels discrimination in the workplace. Many employers avoid hiring people with obesity, however competent the person might be.



## Personal finances

Some persons with obesity are unemployed or have lower-paying jobs, which leads to lower incomes and financial difficulties.



## Housing

Landlords may avoid renting to persons with obesity.



## Obesity as a chronic disease:

### Consequences for you as a patient

The World Health Organization (WHO) defines obesity as a disease when excess or abnormal adiposity (severe overweight) impairs health and well-being.<sup>16</sup>

Obesity is not your fault, as it can never be anyone's fault that they have a chronic disease.

### How is obesity diagnosed?

Obesity must be diagnosed by a qualified health professional based on a full clinical assessment designed to understand a person's health, weight, and psychosocial history, as well as a physical exam.

A common misconception is that obesity can be diagnosed using a simple measure such as the Body Mass Index ( $BMI = \text{weight [kg]} / \text{height [m]}^2$ ). Although such measurements are useful for population-based studies, they are not sufficient to diagnose obesity. BMI is merely a screening tool used to trigger a full medical assessment and diagnosis. Rather than self-diagnosing using BMI, individuals should obtain a complete medical assessment and diagnosis from a qualified health care professional.<sup>17</sup>

### What causes obesity?

Another common misconception is that obesity is caused, quite simply, by overeating and not exercising enough. But people gain weight for many different reasons! Current research shows that obesity is often hereditary and can be linked with metabolic disorders, stress and hormonal functions, as well as lifestyle factors such as exercise and the kinds of food you eat.<sup>1</sup>

Therefore, different things can trigger obesity for different people. What triggered your obesity may not be what triggered the disease in another person.

### Is there a cure for obesity?

Another common misconception is that there is a cure for obesity. As for any other chronic disease there is currently no cure for obesity. The term "chronic" implies that it is a lifelong disease because once the treatment stops, the disease comes back.<sup>18</sup>

Consider, for example, diabetes. Since there is no cure for diabetes, persons living with diabetes need to have treatment for the rest of their lives. If a person with diabetes stops their treatment, the disease will not only come back but may also progress at a much faster rate. Obesity works in much the same way.

To be clear, obesity is treatable or manageable, but not curable. It is a life-long disease that can be managed using evidence-based and person-centered treatments with long-term support. But no one treatment works for everybody.



## What is the treatment for obesity?

Unfortunately, society continues to fuel the misconception that obesity can be prevented and managed entirely by just eating less and exercising more.<sup>19</sup> This means that individuals with obesity are left to find treatments outside of the healthcare system and without any social support. These treatments often include extreme fad diets and exercise programs which have very high failure rates.

Extreme dieting and exercising are not the way forward! Instead, these practices can have a detrimental effect on psychological health and well-being and can lead to a higher risk for obesity.<sup>5</sup>

One reason is that every time a person who tries and fails an extreme “diet and exercise” program, they slowly start to believe that the problem is with themselves, when it actually is the other way around. It is not the person who has failed the program, it is the fad “diet and exercise” program that has failed the person.

The other reason is that when you follow an extreme diet and exercise program, you starve your body, which responds by resisting weight loss and activating a wide range of hormones that promote more weight gain.

There are several kinds of treatments available which work for many people. Treatments are often used in combination, but no one treatment works for everyone!



### Behavioural change

All chronic disease management interventions involve behaviour change components. In the case of obesity management, behaviour change strategies exist within a spectrum of evidence-based treatments such as nutritional, physical activity, pharmacotherapy, and surgical interventions.



### Medication

As with any chronic disease, medications may be indicated for obesity management. These medications can help when behavioural changes alone have not been effective. It is important to know that responses to these medications vary from person to person.<sup>20</sup>



### Surgery

Surgery may be appropriate for those with severe obesity and it must always be followed up by qualified health professionals. But even if the surgery is successful, obesity remains a life-long issue. Often those who have had surgery will need continuous support, such as behavioural interventions, medications, and other assistance to improve their health.<sup>4</sup>



### Healthy eating and exercise

Healthy eating and exercise patterns are important components of any chronic disease prevention and management program (i.e., not just obesity). Choose a healthy eating and exercise pattern that improves your health and works for you over time and remember that there is no one-size-fits-all approach.



## What is the goal of obesity management and treatment programs?

As with any other chronic disease, management or treatment for obesity should focus on improving health. Therefore, obesity management is about much more than weight loss.

One reason for this is that weight loss can be very difficult to achieve, depending on what drives weight gain for that particular individual. Another reason is that treatment effects will vary from person to person. One person may lose a lot of weight using one treatment, while another may not lose any weight at all.

Obesity treatments must be personalized to meet the needs of each individual. The treatment must align with your life context and be manageable and sustainable if it is to be successful!<sup>21</sup>

## Weight is not a behaviour!

It is important to know that weight is not a behaviour! There are many factors beyond an individual's control that regulate body weight (e.g., genetics, hormones, psychosocial conditions). Furthermore, weight loss may or may not happen if you improve your eating or exercise behaviours, even though there are great health benefits from healthy eating and exercise patterns.

# Living with obesity:

## The role of self-care in obesity management

Living with a chronic disease requires both medical management and self-care. The task — and the opportunity — is to live with obesity in a healthy and enjoyable manner. Based on our current understanding of chronic disease management, it is possible for individuals with obesity to live long and happy lives.

**Self-care or self-management** is at the core of any chronic disease management plan. Building your self-esteem, body confidence and self-efficacy is part of self-management and living well with obesity. There is no single pathway that will work for everyone. Your self-care plan will depend on your needs, preferences and life situation.

Think about what you can do for yourself and find support to go through with it. Find ways to cope with the problems and challenges — emotional as well as practical — that will come up along the way. Your self-care plan will also need to be coordinated with medical interventions in consultation with your doctor.

Addressing internalized weight bias is important because it can affect behavioural and health goals. There are ways to address internalized weight bias that are rooted in principles of acceptance and commitment therapy as well as cognitive behavioural therapy. Talk to your healthcare provider to find out what strategies and supports that can work for you.

People come in different shapes and sizes. Aiming to achieve a “normal” or “ideal” weight may not be appropriate. Good health and an enjoyable life may be a better goal. No weight gain, only a little weight gain, or just a few kilos weight loss is often good enough! That way, you don’t have to deal with going back and forth between quickly losing maybe a lot of weight, and then gaining most of it back or maybe even more, which will you make you feel like a failure.

### Maslow’s Hierarchy of Needs

One way to think about self-care in obesity management is using theories of psychology. Maslow’s Hierarchy of Needs, for example, can help us understand our intrinsic motivation for behaviour change and self-care.<sup>22</sup> Think instead about satisfying your needs, starting with the lower levels and working your way up. Find yourself a comfortable place to be, with warmth, clean air, good food, rest and whatever else you need on the physical level.

Then think about what you need for safety and stability in your life, whether it be physical safety or economic. Go on to think about finding people and social situations that are good for you. Work on building up your own self-esteem, self-confidence and sense of identity.

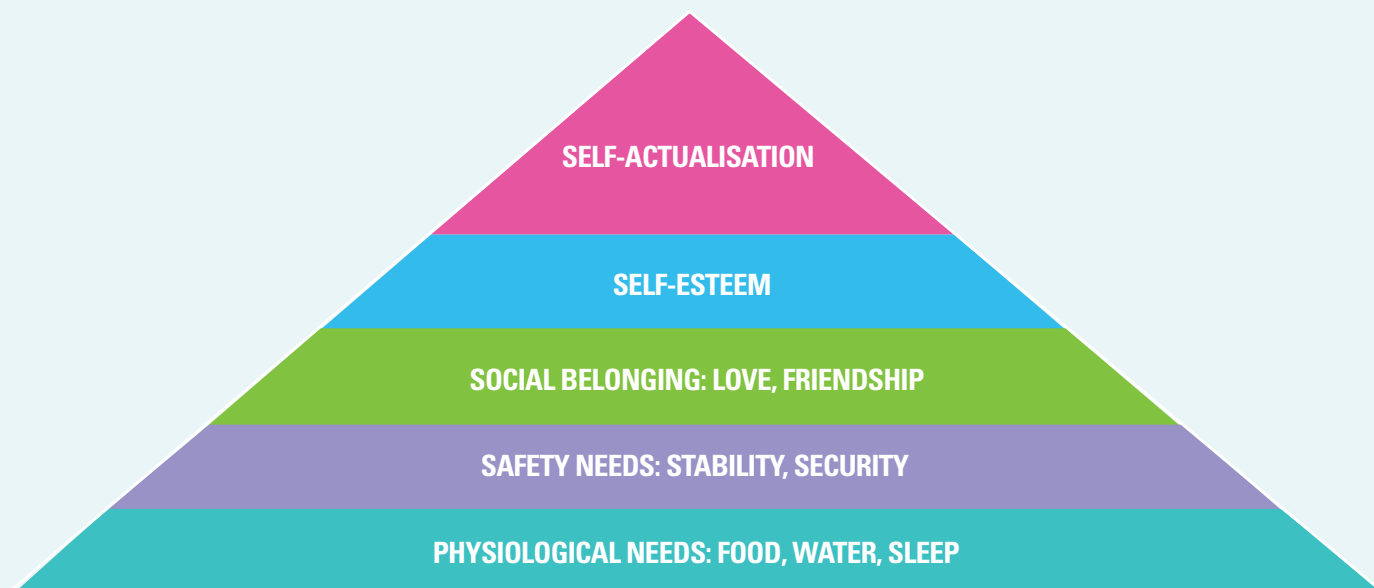


Figure 1: Maslow’s Hierarchy of Needs



# Weight loss is not the answer to everything!

We have heard so many times that “if you lose weight all your problems will be solved” — but that is not always the case. There are specific problems that relate directly to weight, many of them having to do with the physical body. And yes — if you lose weight you will change your body, but not necessarily solve the problems around it.

There can be some unintended consequences to obesity treatments and weight loss. You may feel uncomfortable with how your body has changed. You may experience physical discomforts. For example, when you lose fat, you may end up with excess skin that can impact your mobility and functioning.

Surprisingly, your body doesn't simply adapt to the weight loss and initially the weight loss may be more of a strain on the body. Standing on the scale and getting positive points for having lost a major part of the extra fat you carried you might not feel comfortable after all. For example, the excess skin may prevent you from purchasing clothes that you had dreamt of having or from doing the things that you were hoping to do, such as exercising or travelling.

## Obesity treatment may impact your identity

When you lose weight, you have to build a new relationship with yourself from a totally different perspective. It will take a long time for your mind to adjust to the changes in your body.

This may be a very painful process. Feelings of conflict can be a heavy burden, not only for you but for people around you.

You may also need to change your relationship to the world around you. You might feel as though you are in another country with an unknown culture! This “outside normal” state might develop with your family, close friends, school/work and your general living situation.

Most people are uncomfortable with change, even if it is in the best of directions. But you have to re-orient yourself and find “life safety”, which means changing “your costume” and finding your personal comfort zone.

### Reactions from family and friends

When your body changes and you lose weight, your family and your friends will react in different ways. You might — to your surprise — even be met with hostility because it changes the balance of their social life too. Unaware of this, your friends might even in a subtle way encourage you to gain weight and return to your former self because they are not ready to deal with this change.

### Treatment is not always successful

Attempts to change the physical body, whether by means of medical treatment, behavioural interventions or surgical procedures are not always successful and, even when they are successful, may not be sufficient to bring about an improved quality of life. The reality is that we do not have effective obesity treatments that work for everyone. Remember, if the treatment does not work for you, it does not mean that you have failed. Family and friends may not be aware of the current scientific and clinical understanding of obesity and may also cast blame and shame on you for failed attempts at managing obesity. This means that we need to advocate for better treatments and educate our families and friends about obesity.

## Personal Recovery

To stop the negative spiral of stigma and poor quality of life, it is necessary to find a way to other, more positive personal and social processes. One of these is recovery.

We are not speaking here of medical recovery ("clinical recovery") by means of treating symptoms or losing weight. We are speaking of personal recovery, which is about the patient's own perspective on reclaiming his or her life.<sup>23</sup>

The recovery process has several components, which can be described as:

- **Acknowledging one's disease, rejecting the stigma.** The disease of obesity, no matter what it means for your physical body, is not your whole self or your whole life. Obesity does not define you as a person.
- **Coping.** Finding ways to live with obesity and various health problems that may be connected.
- **Rebuilding positive personal and social identity.** Dealing with the impact that stigma and weight bias has had on your life and defining a new positive life for yourself as a person living with obesity.
- **Connectedness.** Building and rebuilding personal and family relationships and finding a place in the wider society.
- **Hope and optimism about the future and finding meaning and purpose in life.** It takes time life with obesity can be a good life and there is hope for a better life as your recovery process goes on.

## Support in your personal recovery

- A doctor and other health care professionals can help you manage your disease.
- A psychologist, counselor, coach or other professional can help you to handle the emotional side of managing your psychosocial health and living with obesity while facing both internal and external stigma.
- Exercise, but in ways and amounts that are appropriate for you and your condition. Aquagym is good for many people, daily walks (with a dog?) or whatever is good for you!
- Support from other people who are living with obesity. The best experts and the best support can come from other people who experience similar problems.

### Personal recovery:

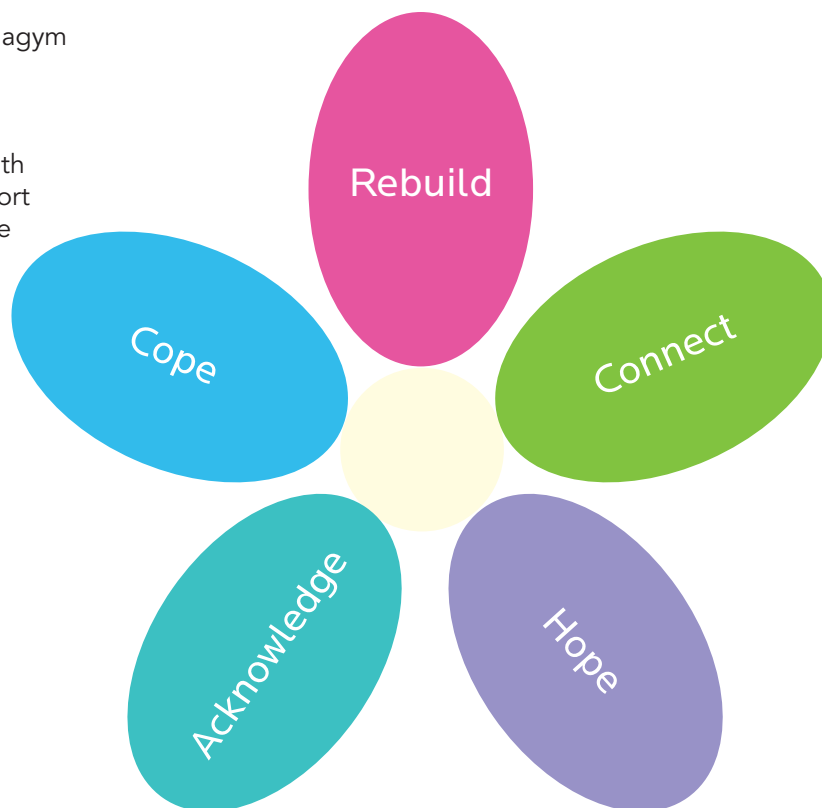
Acknowledge

Cope

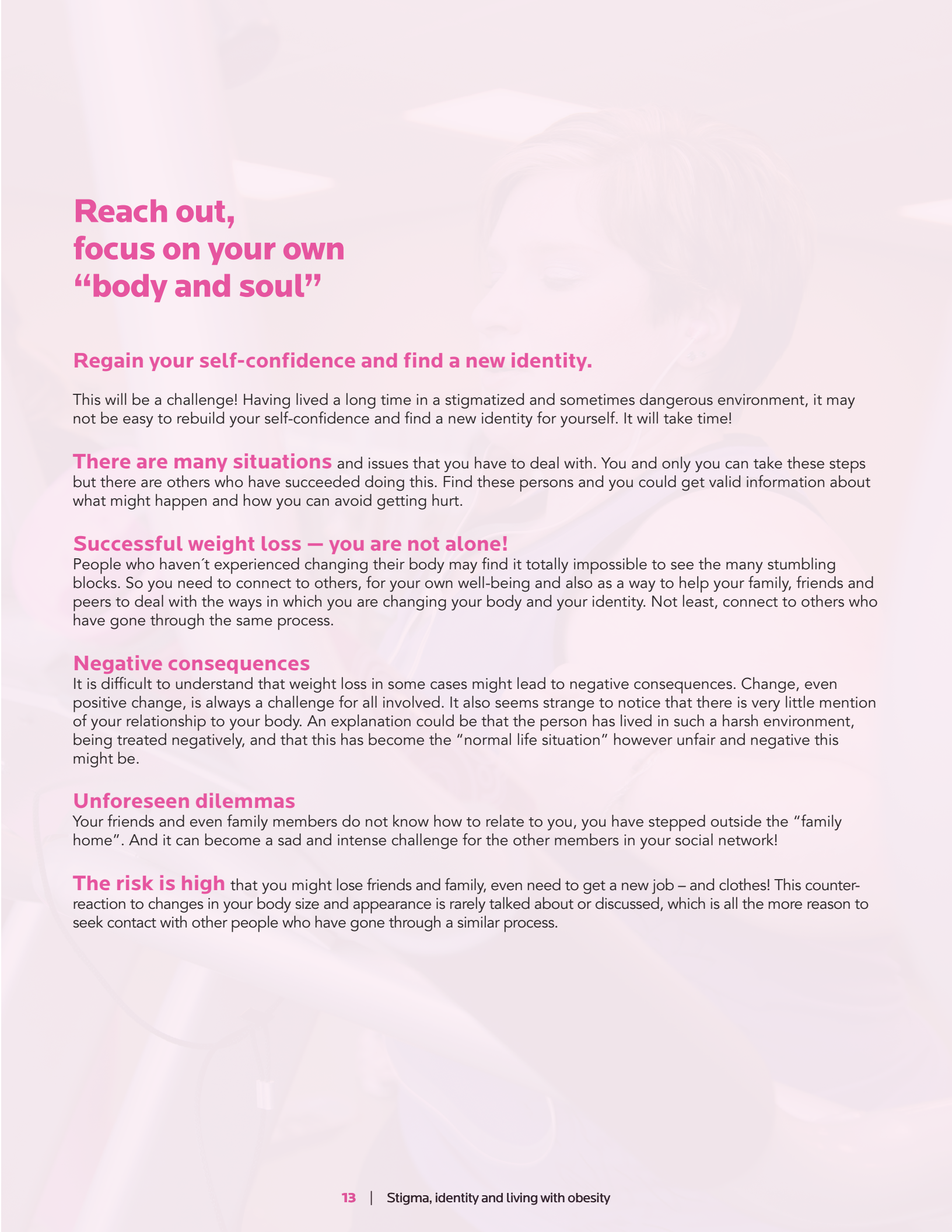
Rebuild

Connect

Hope







## Reach out, focus on your own “body and soul”

### Regain your self-confidence and find a new identity.

This will be a challenge! Having lived a long time in a stigmatized and sometimes dangerous environment, it may not be easy to rebuild your self-confidence and find a new identity for yourself. It will take time!

**There are many situations** and issues that you have to deal with. You and only you can take these steps but there are others who have succeeded doing this. Find these persons and you could get valid information about what might happen and how you can avoid getting hurt.

### Successful weight loss — you are not alone!

People who haven't experienced changing their body may find it totally impossible to see the many stumbling blocks. So you need to connect to others, for your own well-being and also as a way to help your family, friends and peers to deal with the ways in which you are changing your body and your identity. Not least, connect to others who have gone through the same process.

### Negative consequences

It is difficult to understand that weight loss in some cases might lead to negative consequences. Change, even positive change, is always a challenge for all involved. It also seems strange to notice that there is very little mention of your relationship to your body. An explanation could be that the person has lived in such a harsh environment, being treated negatively, and that this has become the “normal life situation” however unfair and negative this might be.

### Unforeseen dilemmas

Your friends and even family members do not know how to relate to you, you have stepped outside the “family home”. And it can become a sad and intense challenge for the other members in your social network!

**The risk is high** that you might lose friends and family, even need to get a new job – and clothes! This counter-reaction to changes in your body size and appearance is rarely talked about or discussed, which is all the more reason to seek contact with other people who have gone through a similar process.

# Self-reliance

All of the issues have to do with taking charge of your health and life. This “self-reliance” is your own capacity to take charge of your own life and your own health.

Self-reliance can be described in five components:

- Focus on health and quality of life (not weight loss).
- Consider action options. What can you do about your health and about the stigma from society that you are facing?
- Accept responsibility, not guilt. Obesity is not your fault, but you can do something about it by talking to a qualified health care professional and engaging in self-care!
- Find or create support community. You are not alone. Find people, organizations or groups that are good for you.
- Be patient! Change takes time. Don't try to rush it, let it take the time it needs.

## Patient engagement — see yourself as an expert!

As a patient and user of various health services, you have a right to be respected, listened to and to work in collaboration with your healthcare providers who can give you access to evidence-based care and treatments.

In many ways, you are the greatest expert on what is best for when you have the right information and access to necessary help and support. In addition, being involved in your own treatment leads to increased self-respect, self-confidence and a positive sense of identity.

All of these things are important in your process of personal recovery and taking charge of your own life and health.

Therefore, don't let your doctor or other health care professionals make the decisions for you, without your input! See to it that you share in the decision-making and in shaping your own disease management plan and life!

## Create your own supportive environment

Find people, places and activities that are good for you. If people near you are weight-biased, and stigmatizing towards you and are making you feel guilty about yourself and your body, don't give them that space! Find other people instead, people who will support you in a positive way.

## Get support from other patients and users

One way of finding support is from other patients and people who have similar problems who are taking steps to change their lives.

**Remember:**

- **You are not alone;**
- **You should be in good company;**
- **You are one of a group of aware healthcare users; and**
- **You should be part of the decision-making process!**

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