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## Health State Descriptions for Canadians

# Health State Descriptions for Canadians: Diabetes

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## Health state descriptions for Canadians: Diabetes

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This document is one of a series that covers the major disease groupings that affect Canadians. The series is primarily intended to document the disease classifications used in the Population Health Impact of Disease in Canada research program and help researchers to understand how the PHI estimates were calculated. It is also of interest to health professionals, advocacy groups, and individual Canadians who are looking for an overview of how living with diabetes affects day-to-day functioning.

The PHI is a collaboration of Statistics Canada, the Public Health Agency of Canada, and researchers from McGill University, the University of Ottawa, the University of Manitoba, the Institute for Clinical Evaluative Sciences (ICES) and l'Agence de développement de réseaux locaux de services de santé et de services sociaux de la Montérégie. The PHI is funded by Statistics Canada and the Public Health Agency of Canada.

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## Health State Descriptions for Canadians:

### *Diabetes*

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#### **Note of appreciation**

Canada owes the success of its statistical system to a long-standing partnership between Statistics Canada, the citizens of Canada, its businesses, governments and other institutions. Accurate and timely statistical information could not be produced without their continued cooperation and goodwill.

## Context: Health state descriptions for Canadians



This document provides standardized descriptions for the main health states associated with the progression and treatment of a disease. These descriptions are the first step in measuring how living with a disease and its treatment affects health-related quality of life in terms of physical, mental, and social well-being.

Underlying this approach is a new tool to measure functional health. Among other attributes, pain, limitations to physical functioning, or anxiety can limit an individual's ability to participate in day-to-day activities. We classify these using the Classification and Measurement System of Functional Health (CLAMES), with eleven such attributes that span physical, social and mental well-being. For each attribute, there are four or five levels ranging in severity from no limitations in the attribute to severe limitations. Level 1, for instance, represents no limitations; for the attribute describing pain and discomfort it would read "generally free of pain and discomfort." Table 1 shows the complete list of levels for each attribute.

For each health state, we describe a "typical" case, based on a combination of literature review and expert consultation. Although every individual's experience of a given disease will be unique, creating these general descriptions is necessary for measuring health at the population level.

The first step in this process involves conducting an extensive review of the literature on a particular disease, in order to collect information on the main types of the disease, the usual progression, symptoms, and resulting functional limitations, and typical treatment options and their effects.

This evidence is then synthesized in order to create the health state classifications. Essentially, each health state is classified according to 11 CLAMES attributes to represent its overall consequences for functional health. In this way, a large amount of information on the typical experience of a disease is condensed into a more manageable form, which facilitates measurement of the impact of the disease on the population. Next, in order to ensure their clinical accuracy, the health state descriptions and classifications are reviewed by medical experts and revised accordingly.

The classifications are used to elicit preference scores from panels of Canadians based on techniques grounded in utility theory. Preference scores, which indicate the relative preference for a health state compared with full health, help us understand how Canadians view the various aspects of functional health. Along with data on incidence and duration, preference scores contribute to estimates of the impact on the Canadian population of both disease and risk factors that contribute to them.

Measured in terms of years of life lost to premature mortality and year-equivalents of reduced functioning due to the disease, these estimates allow us to determine how many years of life—and how many years of healthy living—are lost due to specific diseases and risk factors. They provide answers to questions such as "what would be the impact of reducing obesity on the health of Canadians?" both in terms of lives saved and in terms of increased health over their lifespan.

For further details on the Population Health Impact of Disease in Canada (PHI) research program, the process of creating the health state descriptions and classifications, and the development of population estimates to which they contribute, please consult the PHI website at <http://www.phac-aspc.gc.ca/phi-isp/index.html>.

**Table 1**  
**Classification and Measurement System of Functional Health (CLAMES)**

**Core attributes**

**Pain or discomfort**

- 1 Generally free of pain and discomfort
- 2 Mild pain or discomfort
- 3 Moderate pain or discomfort
- 4 Severe pain or discomfort

**Physical functioning**

- 1 Generally no limitations in physical functioning
- 2 Mild limitations in physical functioning
- 3 Moderate limitations in physical functioning
- 4 Severe limitations in physical functioning

**Emotional state**

- 1 Happy and interested in life
- 2 Somewhat happy
- 3 Somewhat unhappy
- 4 Very unhappy
- 5 So unhappy that life is not worthwhile

**Fatigue**

- 1 Generally no feelings of tiredness, no lack of energy
- 2 Sometimes feel tired, and have little energy
- 3 Most of the time feel tired, and have little energy
- 4 Always feel tired, and have no energy

**Memory and thinking**

- 1 Able to remember most things, think clearly and solve day-to-day problems
- 2 Able to remember most things but have some difficulty when trying to think and solve day-to-day problems
- 3 Somewhat forgetful, but able to think clearly and solve day-to-day problems
- 4 Somewhat forgetful, and have some difficulty when trying to think or solve day-to-day problems
- 5 Very forgetful, and have great difficulty when trying to think or solve day-to-day problems

**Social relationships**

- 1 No limitations in the capacity to sustain social relationships
- 2 Mild limitations in the capacity to sustain social relationships
- 3 Moderate limitations in the capacity to sustain social relationships
- 4 Severe limitations in the capacity to sustain social relationships
- 5 No capacity or unable to relate to other people socially

continued on next page...

## Supplementary attributes

### Anxiety

- 1 Generally not anxious
- 2 Mild levels of anxiety experienced occasionally
- 3 Moderate levels of anxiety experienced regularly
- 4 Severe levels of anxiety experienced most of the time

### Speech

- 1 Able to be understood completely when speaking with strangers or friends
- 2 Able to be understood partially when speaking with strangers but able to be understood completely when speaking with people who know you well
- 3 Able to be understood partially when speaking with strangers and people who know you well
- 4 Unable to be understood when speaking to other people

### Hearing

- 1 Able to hear what is said in a group conversation, without a hearing aid, with at least 3 other people
- 2 Able to hear what is said in a conversation with 1 other person in a quiet room, with or without a hearing aid, but require a hearing aid to hear what is said in a group conversation with at least 3 other people
- 3 Able to hear what is said in a conversation with 1 other person in a quiet room, with or without a hearing aid, but unable to hear what is said in a group conversation with at least 3 other people
- 4 Unable to hear what others say, even with a hearing aid

### Vision

- 1 Able to see well enough, with or without glasses or contact lenses, to read ordinary newsprint and recognize a friend on the other side of the street
- 2 Unable to see well enough, even with glasses or contact lenses, to recognize a friend on the other side of the street but can see well enough to read ordinary newsprint
- 3 Unable to see well enough, even with glasses or contact lenses, to read ordinary newsprint but can see well enough to recognize a friend on the other side of the street
- 4 Unable to see well enough, even with glasses or contact lenses, to read ordinary newsprint or to recognize a friend on the other side of the street

### Use of hands and fingers

- 1 No limitations in the use of hands and fingers
- 2 Limitations in the use of hands and fingers, but do not require special tools or the help of another person
- 3 Limitations in the use of hands and fingers, independent with special tools and do not require the help of another person
- 4 Limitations in the use of hands and fingers, require the help of another person for some tasks
- 5 Limitations in the use of hands and fingers, require the help of another person for most tasks

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## Diabetes



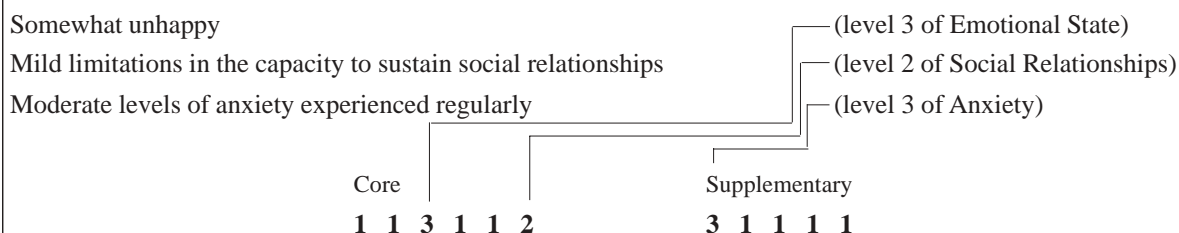
## Note to reader

### How to read the classification:

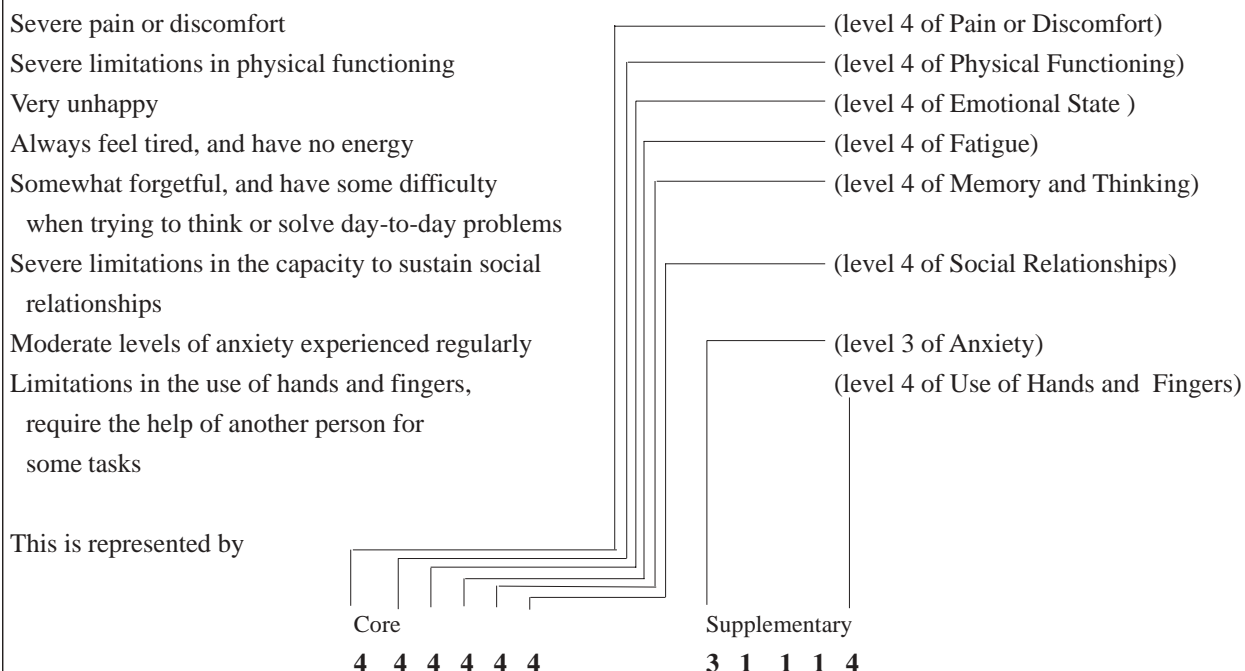
Health states are classified using eleven attributes, each with 4 or 5 levels. Level 1 indicates no limitations, while level 4 or 5 are the most severe limitations. **Please note that these levels are a shorthand for the classification: they are not measurements on an interval scale.**\* A complete list of the attributes and levels appears as Table 1.

As an example, we can look at two health states related to cancer, the first describing a health state at diagnosis and the second describing a health state for the last month of life, during terminal care.

Individuals with early stage breast cancer could be described by the following:



By contrast, the following describes terminal care:



**Classification of the major health states in the progression and treatment of diabetes are provided in the Summary table.**

\* For instance, the difference between level 1 and level 2 is not the same as between level 3 and level 4. In addition, attributes are not equally important in terms of health state preferences. For more information on health state preferences developed from these scores, please see <http://www.phac-aspc.gc.ca/phi-isp/index.html>.



**Summary table:  
Classification of health states related to diabetes**

Health state	Attribute and level										
	Pain or discomfort	Physical functioning	Emotional state	Fatigue	Memory and thinking	Social relationships	Anxiety	Speech	Hearing	Vision	Use of hands and fingers
<b>Health states for diabetes</b>											
Type 1 diabetes, chronic, uncomplicated	2	1	2	2	1	2	2	1	1	1	1
Type 2 diabetes, chronic, uncomplicated	2	1	1	2	1	1	2	1	1	1	1
Gestational diabetes	2	1	1	2	1	1	3	1	1	1	1
<b>Sequelae</b>											
Diabetic retinopathy, chronic, proliferative and non-proliferative	2	3	3	2	1	2	3	1	1	3	1
Diabetic neuropathy, chronic	3	3	2	2	1	2	2	1	1	1	2
Diabetic foot, chronic	3	3	1	2	1	2	3	1	1	1	1



## Introduction

Diabetes is a disease in which the body does not produce enough insulin or does not use insulin properly. Insulin is a hormone that allows glucose (sugar) to enter body cells where it is used as energy. With little or no insulin, glucose remains in the bloodstream instead of being used as fuel. High blood sugar levels are associated with diabetes. Treatment is aimed at keeping blood glucose near normal levels at all times, often by means of multiple insulin injections daily. Normal blood glucose levels are between 4.0 and 7.0 mmol/L when fasting, and between 5.0 and 10.0 mmol/L two hours after eating.<sup>1</sup> Fasting levels between 6.1 and 6.9, however, may be evidence of pre-diabetes. If diabetes is improperly managed or left untreated, the high levels of blood sugar can increase the risk for serious complications.

Diabetes is the 6th leading cause of mortality in the world among adults aged 60 years and over.<sup>2</sup> In 1999-2000, about 5.1% of the Canadian population aged 20 and over, or 1.2 million Canadians, were living with diabetes diagnosed by a health professional.<sup>3</sup> Prevalence increases with age, peaking at 15.5% in the 75-79 year age group, and is generally higher among men than women.<sup>3</sup> Age-standardized rates among Aboriginal peoples are triple the rates in the general population.<sup>4</sup>

However, studies suggest that there is a hidden burden from cases that go undiagnosed, which is

estimated to be about one third of all diabetes cases. Using an adjustment factor\* to account for undiagnosed cases, the estimated prevalence of diagnosed and undiagnosed cases could be as high as 1.8 million.

Diabetes results in both premature death and a reduction of functional health. This is due, in part, to the variety of complications that are associated with persistently high blood glucose levels over long periods of time. Health-adjusted life expectancy (HALE), a measure that combines the effects of morbidity and mortality associated with disease by adjusting for the years lived in less than full health, is reduced for both men and women living with diabetes. The HALE for men in Ontario is 58.3 years compared to 70 years for those without diabetes, while for women the HALE is 63.8 years for those with diabetes compared to 73.5 years for those without the disease.<sup>6</sup>

Many aspects of quality of life are affected by diabetes and its associated treatments. For instance, mild limitations are seen across many attributes of functional health, such as pain and discomfort (often due to needles required for injections), anxiety and fatigue. More severe impacts on functioning are not usually experienced until sequelae develop.

Complications of diabetes are caused by persistently high blood glucose levels, blood

\* An inflation rate is calculated based on an adjustment factor of  $1/(1-0.33)$  — the 0.33 being the estimated percentage of undiagnosed cases<sup>5</sup> — which equals 1.49. The adjustment factor multiplied by the number of diagnosed cases provides an estimate of total cases (diagnosed and undiagnosed).

pressure and cholesterol; months and years of elevated levels can damage the blood vessels and nerves, increasing the risk for heart disease, blindness, nerve and kidney damage, and skin complications (e.g., bacterial and fungal infections, diabetic dermopathy).

This document presents the two main types of diabetes, type 1 and type 2. Type 1 diabetes is an autoimmune disorder that results in the body's failure to produce insulin and is generally diagnosed in children and young adults. Type 2 diabetes can result from insulin resistance, or from the loss of the body's ability to produce sufficient insulin. Type 2 diabetes is more common in the older population.

Gestational diabetes, experienced by pregnant women who did not have diabetes prior to pregnancy, is also presented here. Gestational diabetes is a temporary condition that is usually remedied once the pregnancy is over. It affects two to four percent of all pregnancies<sup>7-10</sup> and greatly increases the risk of developing diabetes later in life. In the International Classification of Diseases,<sup>11</sup> gestational diabetes is considered a complication related to pregnancy, and is coded

under "Other conditions of the mother that complicate pregnancy"(648), "Gestational diabetes" (648.8).

This document also presents the most common sequelae of both type 1 and type 2 diabetes, including diabetic retinopathy, diabetic neuropathy, and diabetic foot. Two of these fall under other ICD-9 chapters: diabetic retinopathy falls under the classification of diabetes with ophthalmic manifestations (ICD-9 250.5) and is further classified within diseases of the nervous system and sense organs under diabetic retinopathy (362.0). Diabetic neuropathy is first classified under ICD-9 250.6, diabetes with neurological manifestations and then under musculoskeletal diseases as arthropathy associated with neurological disorders (713.5).

Complications that are sequelae of both diabetes and other diseases are presented in other documents in this series. These complications include blindness (Nervous System and Sense Organ Diseases), amputation (Injuries), ischemic heart diseases and stroke (Cardiovascular Diseases), chronic renal failure and end-stage renal disease (Genitourinary Diseases).



## Health states for diabetes

### Type 1 diabetes, chronic, uncomplicated ICD-9 250.01

#### Description

Type 1 diabetes occurs when the body produces little or no insulin. The exact cause is unknown, but research suggests that the body’s immune system attacks and destroys the beta cells in the pancreas that produce insulin. Genetics is also a potential contributing factor for type 1 diabetes, as risk increases with a family history of the disease. Previously labeled insulin-dependent or juvenile diabetes mellitus, type 1 diabetes is a chronic condition that is usually diagnosed in children and young adults.

Treatment requires a strict regimen that includes a carefully calculated diet, planned physical activity, home blood glucose testing several times a day, and multiple daily insulin injections. This regimen, though effective at slowing down complications of the disorder, has many implications on a diabetic individual’s health state and social life.

In particular, mild pain and discomfort are often experienced due to needle injections and blood sugar monitoring, sometimes causing sensitivity on the tips of fingers. Mild levels of anxiety can result from fear of injections and fears of complications in the future. In fact, one report indicated that 45% of insulin users avoided injections due to anxiety.<sup>12</sup> Fatigue is also a symptom of diabetes.

The majority of individuals with type 1 diabetes use multiple insulin injections daily to treat the disease. This, along with rigorous diets and careful consumption of sugar, interferes with normal life and thus causes mild limitations in the capacity to sustain social relationships. Type 1 diabetes can also affect the emotional state.

#### Classification

##### Core

**2 1 2 2 1 2**

##### Supplementary

**2 1 1 1 1**

## Type 2 diabetes, chronic, uncomplicated

### ICD-9 250.00

#### Description

Type 2 diabetes results from insulin resistance, a condition in which the body can not properly use the insulin it produces, or from the body's inability to produce enough insulin. Individuals can also move from being insulin resistant to not producing enough insulin. Formerly called non-insulin-dependent diabetes or adult-onset diabetes mellitus, type 2 diabetes is the most common type of diabetes, accounting for approximately 90% of cases. Though more prevalent in the older population, it can be diagnosed at any age, even during childhood. Obesity, physical inactivity, poor diet, and stress significantly increase the risk of type 2 diabetes. Having had gestational diabetes and having a family history of diabetes are also associated with an elevated risk.

Type 2 diabetes is controlled by keeping blood sugar near normal levels. This is typically achieved through diet control, exercise, home blood glucose testing, oral medications and/or insulin (about 40% of individuals with type 2 diabetes require insulin injections).<sup>13</sup> Weight loss can also help to bring blood sugars into the normal range, as approximately 80% of people who develop type 2 diabetes are overweight.<sup>14</sup> In the absence of complications, most individuals with type 2 diabetes feel similar to those with type 1. Needles are required to test blood glucose levels and therefore mild levels of pain and discomfort are experienced. Fatigue is common, and mild levels of anxiety result from fear of complications.

#### Classification

##### Core

**2 1 1 2 1 1**

##### Supplementary

**2 1 1 1 1**

## Gestational diabetes

### ICD-9 648.8

#### Description

Gestational diabetes is diagnosed in pregnancy, generally after the 24<sup>th</sup> week. Hormonal changes associated with pregnancy and the growth demands of the fetus increase insulin needs to two to three times the normal level. If the body can not produce enough insulin, glucose stays in the blood stream and causes high blood sugar levels, resulting in diabetes. Gestational diabetes occurs in two to four percent of all pregnancies.<sup>7-10</sup> About 40% of women who are diagnosed with gestational diabetes will develop type 2 diabetes later in life; <sup>9,15</sup> one in three will develop gestational diabetes again in a subsequent pregnancy.<sup>16</sup> The child is also at increased risk of developing diabetes later in life.

Description

Gestational diabetes can, in most cases, be managed by diet and exercise alone. It is rare that women require insulin treatment in order to control blood sugar levels, but when required, these treatments reduce risks to the mother and the baby. Risks to the mother include the possibility of a Caesarian section delivery or the development of pregnancy-induced high blood pressure. Risks to the infant include macrosomia (fetal weight greater than the 90<sup>th</sup> percentile for gestational age or over 4,000 grams), respiratory distress syndrome, low blood calcium, and neonatal hypoglycemia (low blood sugar). Gestational diabetes is resolved after the baby is born.

The impacts of gestational diabetes on the mother's quality of life affect several attributes of functional health. Mild levels of pain and discomfort are experienced due to needles for monitoring blood glucose levels. Moderate levels of anxiety are experienced due to the possibility of complications during pregnancy and delivery. Mild fatigue is experienced; however, it may be associated with pregnancy rather than gestational diabetes.

Classification

Core

**2 1 1 2 1 1**

Supplementary

**3 1 1 1 1**



## Sequelae of diabetes

### Diabetic retinopathy, chronic, proliferative and non-proliferative ICD-9 250.5, 362.0

#### Description

Diabetic retinopathy is a disease of the microvasculature of the retina and is caused by high blood sugar. In the early (“non-proliferative” or “background”) stages, the blood vessels in the eye weaken and leak tiny amounts of blood or fluid, causing swelling of the retina. Most often vision remains normal, but there is potential for it to become blurred. In the more advanced (“proliferative”) stage, the blood vessels are blocked or closed and parts of the retina die. New blood vessels form to replace the dead ones, but are fragile and often bleed into the eye, blocking vision. Scar tissue then forms, shrinking or tearing the retina or even detaching it from the back of the eye, often leading to severe visual loss or blindness. The incidence and severity of retinopathy increases with the duration of diabetes, and is likely to be worse if control of the diabetes is poor. Both type 1 and type 2 diabetes present this risk.

Almost all people who have had diabetes for more than 30 years will have retinopathy in various stages of progression.<sup>17-20</sup> It is the leading cause of adult blindness in Canada<sup>21</sup> affecting approximately 400 Canadians every year.<sup>22</sup> Adequate control of diabetes and control of high blood pressure will slow the progression of the disease, and is thus the aim of treatment. Other treatment modalities include laser surgery to seal leaking vessels and vitrectomy (a surgical procedure) for cases of hemorrhage into the eye. Treatment can prevent blindness in most cases.

Diabetic retinopathy affects numerous aspects of a person’s quality of life. Usually individuals with diabetes present with both non-proliferative and proliferative retinopathy, and these are considered together here. Moderate limitations in physical functioning are present. For example, if blindness should occur, as in the proliferative stage, the patient will require a caregiver’s help for special needs that include meal planning and preparation, activities of daily living, urine testing, insulin administration, and foot care.

Description	Blindness can also affect the emotional state, as it can contribute to self-esteem problems related to a loss of independence. Loss of vision can also lead to mild limitations in the capacity to sustain social relationships. Vision loss, change in health status and lack of independence due to blindness can also create anxiety. The risk of blindness is 25 times greater among individuals with diabetes than among those without. <sup>23,24</sup>	
Classification	Core <b>2 3 3 2 1 2</b>	Supplementary <b>3 1 1 3 1</b>

**Diabetic neuropathy, chronic**  
**ICD-9 250.6, 713.5**

Description	<p>Diabetic neuropathy is a disorder that affects nerve tissue in the body. Exact causes are likely different for different varieties of neuropathy, but high blood glucose is a key factor as high blood sugar levels cause chemical changes in nerves, impairing the nerves' ability to transmit signals. Diabetic neuropathy is the most common complication of diabetes, with a prevalence rate of approximately 50% in the diabetic population.</p> <p>Symptoms occur, on average, 10 to 20 years after diagnosis. Numbness and tingling in the feet is often the first sign, though symptoms vary depending on the nerve(s) and part of the body affected. Keeping tight control over glucose levels is important in preventing progression of tissue damage and the onset of further problems. Treatment is aimed at reducing the symptoms using a topical treatment such as Capsaicin, or anti-depressant/anti-epileptic drugs (i.e. Amitriptyline/Gabapentin) to control nerve pain.</p> <p>Limitations are experienced in many attributes of functional health. This description is based on individuals with chronic, medication-controlled diabetic neuropathy. Moderate levels of pain and discomfort are experienced. Severe nerve damage results in a loss of feeling (e.g., pain and temperature) in the area where the neuropathy is present; individuals may experience minor cuts, scrapes, blisters, or pressure sores that they may not be aware of due to the insensitivity. Painful diabetic neuropathy can become physically disabling, resulting in moderate limitations in physical functioning.</p>
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Description	Emotional state is affected, and symptoms of weakness, particularly in the muscles, can be experienced. There are also mild limitations in the capacity to sustain social relationships. This is mainly due to sexual dysfunction; approximately 50% of males with diabetes experience impotence, <sup>25-27</sup> and 35% of females with diabetes experience some form of sexual difficulties. <sup>28</sup> Symptoms in the hands (and lower extremities) that include numbness, tingling, burning, or pain provide potential for limitations in the use of hands and fingers.					
Classification	Core			Supplementary		
	<b>3</b>	<b>3</b>	<b>2</b>	<b>2</b>	<b>1</b>	<b>2</b>
	<b>2</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>2</b>

**Diabetic foot, chronic**  
**ICD-9 250.7**

Description	<p>Diabetic foot is a complication of diabetes that results in infection in the skin, muscles, or bones of the foot. This is a result of the nerve damage and poor circulation associated with diabetes. Because diabetes also alters the immune system, decreasing the body’s ability to fight infection, even small infections can lead to death of the skin and other tissues, leading to deformities and potentially amputation. Foot infections occur most frequently when the foot is exposed to extreme temperatures or dryness, or when corns and calluses are not well maintained. In this case, ulcerations and sores will often develop. Approximately 15% of individuals with diabetes will develop a foot ulceration at some point in their life.<sup>29-31</sup> Over half of all leg amputations occur in people with diabetes.<sup>31</sup></p> <p>Diabetic foot is not a curable condition. However, preventive measures can be taken to reduce the risk of diabetic foot and its effects: inspecting feet every day; wearing shoes and socks at all times; and not smoking. Blood sugar levels, blood pressure and cholesterol should be kept under control; individuals should regularly visit a physician. If infection is present, antibiotics are prescribed to control it.</p> <p>Diabetic foot has many implications for an individual’s health state. In particular, pain and discomfort are experienced at moderate levels, mostly associated with infection or trauma to the foot, although some individuals may not feel pain or discomfort at all. Bed rest is necessary to treat an infected foot, causing moderate limitations in physical functioning, and contributing to mild limitations in the capacity to sustain social relationships. Moderate levels of anxiety are also experienced due to fear of amputation.</p>					
Classification	Core			Supplementary		
	<b>3</b>	<b>3</b>	<b>1</b>	<b>2</b>	<b>1</b>	<b>2</b>
	<b>3</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>

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