Diabetes Prevention and Care Development Programme 2010 – 2020

Based on the National Diabetes Prevention and Care Development Programme Development Strategy 2010 – 2020
Together in reducing the burden of diabetes

National Prevention and Care Development Programme
Development Strategy 2010 – 2020

Ljubljana, April 2010
Together in reducing the burden of diabetes
Dear readers,

You are reading the first National Diabetes Prevention and Care Development Programme of Slovenia, adopted by the Government of the Republic of Slovenia in April 2010.

This programme is the result of co-operation between professionals, policy-makers and the civil society and is based on the recommendations set out in the St Vincent Declaration, a document adopted by the World Health Organization and the International Diabetes Federation setting bases for diabetes management.

There are around 125,000 patients with diabetes in Slovenia, representing more than six per cent of the adult population. Diabetes is a heavy burden for the patients, their families and their friends. They need accessible, high-quality and effective care, ensured by medical professionals of different specialties and levels and allowing for active participation of patients.

Diabetes can be prevented! In addition to early detection of diabetes and a comprehensive care of patients, I would particularly like to stress the importance of a healthy lifestyle. It requires an informed and motivated individual, willing to assume responsibility for his or her health. On the other side, the state must ensure conditions that enable the individual to be able to lead a healthy lifestyle.

This Programme sets out strategic directions for measures in the area of prevention, early detection and medical treatment of diabetes and for monitoring, research and education in the area. It must be considered as an addition to other public health strategies in the management of risk factors and chronic diseases. The entire programme bases on co-operation between partners within and outside healthcare.

I thank to all who have participated in the preparation of the Programme and to those who made it possible for us through their rich experiences and knowledge to prepare a programme that puts an empowered patient into the centre of our attention.

Finally, I would like to invite all acknowledged partners to get actively involved in the realisation of the set goals, as only with joint efforts and co-operation we will be able to achieve lower incidence and better management of diabetes.

Dorijan MARUŠIČ
Minister
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INTRODUCTION

Diabetes is one of the chronic diseases that due to their high prevalence and demanding and complex care represent a major public healthcare problem. Like other chronic non-communicable diseases, diabetes is no longer solely a developed world issue but a reflection of economic and social determinants of health, such as poverty and lack of education. In order to control diabetes successfully, a coordinated co-operation of the healthcare sector and the entire society is needed. In spring 2010, Slovenia adopted the National Diabetes Prevention and Care Development Programme 2010 – 2020, which represents the strategic foundation for taking measures in the area of prevention, early detection and medical treatment of diabetes, and for monitoring, research and education in the area until 2020.

Scale of the problem

According to the World Health Organization (WHO) estimates, there are 246 million adults with diabetes worldwide (5.9 per cent of population). Increasing as well is the number of children with the disease. In addition, 308 million adults have an impaired glucose tolerance (7.5 per cent of the population), a pre-diabetic state. It is expected that by 2025, there will be more than 380 million people with diabetes (7.1 per cent of population) and 418 million adults with impaired glucose tolerance (8.1 per cent of population) worldwide, therefore it is urgent to adopt measures for a better control of diabetes.

The WHO also estimates that 3.8 million people died due to diabetes and diabetes-related health complications in 2007 (6 per cent of all deaths). Around 25 million years of life are lost each year.

There are more than 30 million adults with diabetes in the European Union (EU). The prevalence of the disease in adults increased from 7.6 per cent in 2003 to 8.6 per cent in 2006, and the predictions are that by 2025, more than 10 per cent of the EU population will be living with the disease.

In regard to the frequency and prevalence of diabetes and its causes, Slovenia does not differ significantly from comparably developed countries or from the EU Member States. In Slovenia, there were approximately 125,000 patients with recognised diabetes in 2007, according to an international survey, representing 6.25 per cent of the entire population. In 2006, 9.8 per cent of adults (aged between 20 and 79) had diabetes according to the estimates of the International Diabetes Federation (IDF) and the Federation of European Nurses in Diabetes (FEND).

BOR, 60 years old

“It is of prime importance to be helped! It is also important to be told that as a patient, you bear most of the responsibility for the disease.”
Financial burden

Already now, diabetes represents a heavy burden for the Slovenian healthcare. In 2007, according to data by the Health Insurance Institute of Slovenia regarding the use of drugs and medical devices, around 53,000 patients were treated with drugs in the form of tablets. 16,000 patients were treated with insulin only, while approximately 10,500 patients were treated with both insulin and tablets. Costs of drugs for the management of diabetes represented 6.5 per cent of all costs of drugs and amounted to 20 million euros in total in 2007. Costs of medical devices for people with diabetes represented 30 per cent of all costs for medical devices and amounted to EUR 13.5 million. The costs of hospital care were several times higher than the costs of outpatient care. According to international estimates, at least 40 per cent of costs related to diabetes are indirect and arise due to temporary leave of absence from work and due to lost future earnings.

National Diabetes Prevention and Care Development Programme

Given the large size of the problem, the continuing rise in the number of patients and the burden that diabetes represents for the healthcare system, and in accordance with the goals of the Resolution on National Plan of Health Care 2008–2013, we have in collaboration with professionals and the end users prepared a Diabetes Prevention and Care Development Programme, Development Strategy 2010–2020.

The entire programme bases on co-operation between partners within and outside healthcare system. The Programme specifies the following goals that should be realised in Slovenia in the area of the management of diabetes:

- a reduction of the incidence of type 2 diabetes;
- prevention or postponement of type 2 diabetes in high-risk individuals;
- an improvement in the early detection of diabetes and
- a reduction of complications and diabetes-related deaths.

At the centre of the attention is an empowered patient able to participate actively in the medical treatment process, able to assume full responsibility for his or her health and leading a quality and full life without diabetes complications. Both the prevention of diabetes and the management of patients must be based on professional guidelines, standards and clinical pathways and must take into account the constant development of the profession. The Programme also envisages the establishment of a monitoring system that will enable the control of the effectiveness of preventing and treating diabetes as well as the improvement of the quality of management.

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MIHA, 64 years

"Ever since I was diagnosed with diabetes I've been feeling guilty for getting ill. I know, I have been overweight for all my life, but there are many other people who are also overweight and don’t develop diabetes. Every time I visit my doctor, he tells me that I need to lose weight, and I want to do it too. And then I start to feel even more guilty all over again."
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DIABETES – A HEAVY BURDEN FOR INDIVIDUALS, THEIR FAMILIES AND THEIR FRIENDS

Diabetes (diabetes mellitus) is a group of different diseases sharing a raised concentration of glucose in blood, commonly referred to as raised blood sugar. Normal levels of blood sugar are maintained by the hormone called insulin, which is produced by the pancreas. When the pancreas does not release enough insulin or when body tissues do not respond to insulin adequately, blood sugar rises above normal levels. Through years, raised blood sugar damages small and large blood vessels and can cause stroke, heart attack, kidney failure, blindness, nerve damage and can combined with the damage to the blood vessels result in amputation. These consequences of raised blood sugar are called diabetes complications. It is possible to detect complications at a very early stage when their progression can be decelerated with high-quality medical treatment. However, it is not yet known how to eliminate them.

There are many types of diabetes:

• type 2 diabetes,
• type 1 diabetes,
• gestational diabetes,
• other types of diabetes

Type 2 diabetes (previously referred to as adult-onset diabetes or non-insulin-dependent diabetes mellitus) is diagnosed in 95 percent of patients with diabetes. Raised blood sugar is a result of simultaneous damage to the pancreas, which does not release enough insulin, and a weakened effect of insulin in body tissues, particularly muscle tissues and the liver. Type 2 diabetes often occurs together with raised blood pressure and impaired lipid metabolism, which is why it is necessary to simultaneously manage raised blood sugar, pressure and lipids.

Type 1 diabetes (previously referred to as adult-onset diabetes or non-insulin-dependent diabetes mellitus) is diagnosed in four per cent of patients with diabetes. Raised blood sugar is a result of damaged pancreas that ceases to secrete insulin or secretes it in very small amounts.

Gestational diabetes is a type of diabetes that first occurs during pregnancy and disappears after the delivery. Women who had gestational diabetes are at high risk of developing type 2 diabetes later in life that is why they need special care.

Other types of diabetes can be caused by medications, operations, malnourishment, infections, genetic syndromes and other rare diseases.

On average, patients with diabetes think of their disease every twenty minutes, every day and for the rest of their lives. That is why diabetes is a heavy burden and influences the quality of patients’ life. Each day, patients are making decisions and are asking themselves things that affect the results of the treatment. Patients are poorly informed about the diabetes complications and fear stroke, heart attack, kidney failure, blindness, amputation etc. In addition to medical treatment, patients need lifelong support of the healthcare team involved in the treatment of diabetes, including physicians of different specialties, diabetes nurse educators and other medical professionals. They need coordinated management of blood sugar, pressure and lipids, active search for early-stage diabetes complications and immediate quality treatment to decelerate the progression of complications.

MAJA, 10 years old

“I took part in a competition about diabetes because my grandma has it. Because we live together I know that she was taking medication and that was she was not to eat certain things. I knew how it was to live with diabetes, but I wanted to know more. Now I know that grandma has type 2 diabetes. I gained a lot of knowledge about healthy diet and physical activity, about the significance of recreation, treatment of diabetes in general and about insulin. Now I eat more healthily and I practice dancing with even greater pleasure.”
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SLOVENIA IS ALREADY TAKING ACTION

In preventing diabetes, Slovenia is one of the countries that have quickly adapted its public healthcare policies to the growing trend of obesity among the adult population and among children. In this relation, we have been consistently carrying out a nutrition strategy for a few years now, an indirect goal of which is also to reduce chronic diseases, including diabetes. We are also carrying out the National Health-Enhancing Physical Activity Programme 2006 – 2011. Both approaches set clear cross-sectoral activities and they involve different partners including the civil society at all levels into joint activities. In the area of the management of chronic disease risk factors, we have been the only European country to carry out a programme regarding the prevention of cardiovascular and several other chronic diseases, which is taking place in outpatient clinics of general and family medicine.

In Slovenia too, inequalities in terms of health are most often a result of economic, social and other determinants of health and are reflected in higher prevalence of risk factors for chronic diseases and poorer results of the provided care. The Pomurje region, where lower economic indicators are also reflected in lower health indicators, has been realizing a successful project of including health into the development strategies of the MURA region and is a model of good practice for other parts of Slovenia.

In Slovenia, based on Health Care and Health Insurance Act, the compulsory health insurance covers the majority of diabetes-related medical costs of patients with diabetes. The accessibility of drugs and medical devices is good but it would need to be upgraded, in particular in terms of greater accessibility to a more comprehensive care including better co-operation at all levels of the healthcare system and greater inclusion of patients. In Slovenia, health insurance also covers the costs of medical treatment with insulin pump of patients under 18 and under certain conditions also for those that are older.

In 2008, Slovenian diabetes experts published the Slovenian Guidelines for the Management of Patients with Type 2 Diabetes to provide a better and unified clinical care to patients with type 2 diabetes in Slovenia. For a better implementation of guidelines and more effective linking of all partners within and outside the healthcare system, including the patients, experts on diabetes have organized first in the Diabetes Forum and in 2009 in the Diabetology Association of Slovenia.

In Slovenia, societies of patients with diabetes have been successfully operating for more than fifty years and have been joining the Slovenian Diabetes Association. Their primary goals are raising awareness among the public about diabetes, informing and connecting patients with diabetes and lobbying for as good a quality of care possible. For many years they have been implementing an innovative project for raising awareness and destigmatising diabetes among the young in the form of competitions in knowledge about diabetes.

LIDIJA, 34 years old
"My mom has to start taking insulin. I'm so scared! Although we are living in the same household, my husband and I are at work and our kids are at school. How is she going to take insulin? Who is going to measure her blood sugar? What if she forgets to eat? What if she goes hypo? The community nurse is going to visit her, I know she will, but mom will still be alone for most of the time."

TJAŠA, 15 years old
"My grandfather is on insulin. The entire family now knows more about diabetes, its complications and the treatment with insulin. We all know how to measure his blood sugar and we know how to help him when he has low blood sugar. He takes insulin on his own and he is so proud that he can do it all by himself. Ever since we've taken classes on the treatment with insulin we've all been eating more healthily."
MANAGING DIABETES IS A CHALLENGE FOR THE ENTIRE SOCIETY

Because of its prevalence and difficult consequences, diabetes is not only a challenge in terms of health but it also represents a wider social care and economic challenge to the society. Diabetes Prevention and Care Development Programme is a strategic document with which we would like to set up and strengthen co-operation among different partners in the society at the state level in order to curb the epidemic and to raise effectiveness in the control of diabetes. The Programme complements other strategies in the area of ensuring health in our state for a wider strengthening of health, managing risk factors for chronic illnesses, managing all chronic non-communicable diseases as well as organizing and financing healthcare in terms of increasing the accessibility and the quality of provided medical care.

The Programme includes the prevention of diabetes and its early detection as well as the care provided to patients with diabetes and the monitoring of the disease. To implement the Programme and therefore successfully realise the goals, the Ministry of Health is adopting biannual action plans, which are approved by the Health Council and which define the processes and specify concrete activities of the key partners. The action plans will enable better co-operation between partners, linking of their activities, monitoring of the results of the endeavours for managing diabetes and sensible upgrades to the measures in the future as well.

LADISLAV, 79 years old

“I’ve had diabetes since I was 28, which means that a year ago I “celebrated” my 50th anniversary of successful co-existence with this incurable disease. I have proven to myself and to others that discipline and self-control are extremely important for managing this type of disease (type 1 diabetes). When I look back on now, I remember how difficult it was to live with diabetes a few decades ago. There were no devices like the ones we have today such as blood sugar meter, new types of insulin, modern devices for injecting insulin and a lot of different literature, there was no counselling by diabetologists and etc. In those days it was hard to live with diabetes, go to work and to control the disease all at the same time. Without the help from my wife who took care of me and my diet, it would have been even much more difficult.”
PRINCIPLES OF THE PROGRAMME

1. **Complementarity** – the Programme complements and upgrades the activities that are carried out in Slovenia to prevent chronic non-communicable diseases and to control them and is connected to these activities.

2. **Equal accessibility** to the programmes of prevention, early detection and treatment of diabetes regardless of social and economic status, age, gender, education or the place of residence.

3. **Comprehensive care** – patients with diabetes must receive coordinated and continuous care during which they are at the centre of attention and which ensures the best possible health outcome.

4. **Quality, effectiveness and safety** of patient care that also includes aspects of mental health and treatment of raised blood sugar, blood pressure and lipids as well as other risk factors for complications, their early detection and treatment, while ensuring the quality of life as high as possible to the patient.

5. **Including and empowering patients** – in addition to education, which ensures the possibility of self-control and diabetes management, patients must be able to have access to information, which will help them decide on their own health and to get included in the process of treatment as active partners and equal members of the team.

6. **Partnership** – formulating and implementing effective approaches to the prevention of diabetes and providing care to patients with diabetes requires cooperation among different partners within and outside the healthcare system, based on shared values, goals, trust, complementarity, a search for mutually agreed solutions and result sharing.

7. **Continuous monitoring** – for planning diabetes management, we need to set up a system of data collection on persons at high risk for developing type 2 diabetes and on patients with diabetes.

8. **Taking into account scientific achievements and ensuring advancement by investing into research and development of the field** – diabetes prevention and the care for patients with diabetes must be based on scientific achievements, professional guidelines, standards and clinical pathways.

**ALENKA, 41 years old**

“During my second pregnancy I had my regular check-up where doctors diagnosed me with impaired glucose tolerance. The last few months before the delivery, I was monitored by a diabetologist at the Ljubljana Polyclinic. She prescribed me a diet and after the participation at a diabetes education programme, I successfully controlled my blood sugar and weight until the delivery. The baby was born healthy and the labour was without complications. Because diabetes during pregnancy predicts a greater possibility of getting this disease later on in life, my general practitioner and I were monitoring my blood sugar on an annual basis. Everything was fine, but three years later I started loosing weight, I was constantly going to the bathroom, I was thirsty all the time and I had blurred vision. The blood test on an empty stomach showed 16.8 mmol/l level of sugar in my blood. The nurse was so upset that she called me at work and told me to come to the outpatient clinic immediately. The doctor referred me to the internal emergency unit, where I was injected insulin for the first time. I've been treated at the Ljubljana polyclinic ever since. Diet and tablets worked only for a couple of months, and I've been treated with functional insulin therapy ever since; diagnosis – type 1 diabetes mellitus. Now, my blood sugar is under control and I live a normal life, the only sacrifice I’m making is with food.”
THE PROGRAMME'S MAIN GOALS

The main goals of the Programme are: to reduce the incidence of type 2 diabetes, to prevent or to delay type 2 diabetes in high-risk individuals, to increase the possibility for early detection of diabetes and decrease complications and mortality related to diabetes.

The incidence of type 2 diabetes needs to be decreased by ensuring the conditions for a healthy lifestyle, by informing the public on the causes for diabetes, by encouraging people to lead a healthy lifestyle and to assume the responsibility for their own health and by ensuring accessibility to all groups of the population to programmes for health protection and strengthening and chronic disease prevention.

Type 2 diabetes in people at high risk for developing this disease needs to be prevented or delayed by recognizing these individuals and their structured care.

The possibilities for early detection of diabetes need to be increased by actively searching for diabetes in persons at high risk for developing type 2 diabetes and by actively looking for the disease in children, adolescents and pregnant women.

Complications and mortality related to diabetes need to be decreased by ensuring access to coordinated, comprehensive, continuous, life-long, effective, safe, high-quality and patient-centred care that must be based on adequate organisation of care and on monitoring its quality, by ensuring possibilities for self-care that must empower patients to manage their diabetes, by continuous education and improvement of skills of medical professional and by educating all persons outside the healthcare system who can make significant contributions in providing care to patients with diabetes.

ELA, 36 years old

“I met Igor a little less than six years ago. When he told me he had diabetes, I realized that I knew almost nothing about the disease. I was surprised, because I thought that diabetics looked “more ill” and that they were dealing with nothing else but their disease throughout the entire course of the day. I didn’t want for the new love of my life to see me as a “complete fool”, so I went to the library where I borrowed every book about diabetes they had, although Igor told me a lot about his disease as well. But most importantly, he gave me a lot of information about what to do if he went hypo. His diabetologist, educators and diabetic society were also helpful.”
CHALLENGES OF THE NATIONAL DIABETES PREVENTION AND CARE DEVELOPMENT PROGRAMME

In certain areas of diabetes management, we are faced with different challenges, which are defined in greater detail in the following paragraphs of the programme. In order to plan and ensure the synergy of acting in action plans and to achieve the set goals, it is necessary for all partners to recognize these challenges.

1. Type 2 diabetes can be prevented

Type 2 diabetes can be prevented by leading a healthy lifestyle.

Risk factors for diabetes that can be influenced with public healthcare measures include bad eating habits, lack of physical activity and the consequent obesity. The measures include the promotion of a healthy lifestyle for all groups of people and ensuring conditions in which we can foster such a lifestyle in all stages of our lives. A special attention must be put on children and adolescents, future parents and groups that are at high risk for developing diabetes and other chronic diseases.

In Slovenia, there are a number of programmes and projects for strengthening health, which are not systematically evaluated and do not grow from a pilot project to an activity accessible to all.

For a healthy lifestyle, conditions must be met in the society for which the healthcare system is not the sole and often even not the key partner.

Health is increasingly connecting with the development of the society and is being established as an economic category.

Policies and measures that are being adopted and implemented by other ministries can have significant impact on health.

Food advertising in the media, particularly those intended for the young, can have a strong influence on the formation of eating habits.

The nutrition policy action plan in Slovenia 2009-2010 envisages regulation of advertising unhealthy foods in accordance with the WHO guidelines.

JELKA, 59 years old

“I’ve had diabetes for many years. It’s a sneaky disease, which at first doesn’t cause you any problems. That’s why other patients often don’t take it seriously.”

META, 45 years old

“Juggling between my work and family, I almost didn’t have any time for myself anymore. I knew it was getting me nowhere. Constant tiredness and headaches were a sign that I needed to completely change my lifestyle including my diet. Otherwise, just like in the case of my mother, I could develop diabetes. I have decided for a tried and tested formula. I watch what I eat and I try to have as much physical activity as possible. My new regime has been well received by my family. Fresh fruit is on the plate every day and almost every weekend we go hiking to the mountains or cycling. I feel much better and I never run out of energy.”
2. People at high risk for developing type 2 diabetes need special care

People at high risk for developing type 2 diabetes can be recognized by a medical check-up that includes some lab tests. These are people with impaired fasting glucose and impaired glucose tolerance or metabolic syndrome. All women who had diabetes during their pregnancy are also at high risk for developing this type. The risk for developing type 2 diabetes can be identified with a questionnaire; in this case lab tests are not necessary so the method is adequate for the use on the population level.

In the healthcare system, there are already options for recognising people at high risk for developing type 2 diabetes, and for its prevention.

Systematic identification of high-risk people and prevention measures must be included into prevention programmes for ensuring healthcare to pre-school and school children as well as adolescents and adults at the primary level of the healthcare system, and into activities of the community pharmacists. The national programme on primary prevention of cardiovascular and other chronic diseases needs to be expanded into all age groups among adults.

Measures regarding risk factor management and type 2 diabetes prevention are incorporated into the activities of the healthcare system.

It is sensible to join prevention activities for preventing type 2 diabetes and the national programme on primary prevention of cardiovascular and other chronic diseases, the scope and manner of implementation of which needs to be adapted. The existing health education centers where activities of the national programme for the primary prevention of cardiovascular and other chronic diseases are being carried out must become a more active and accessible part of the organisational structure for preventing type 2 diabetes at the primary level of healthcare activities.

Amongst people at high risk for developing type 2 diabetes, we need to identify those that have already developed the disease and to include them into high-quality care immediately.

Patients with newly diagnosed type 2 diabetes need to be included into quality, effective and safe care according to clear clinical pathways.

SEBASTJAN, 46 years old

“Both my father and grandfather have diabetes so I always thought by myself I was also likely to develop diabetes. But it was still a big shock for me when it actually happened. I was hoping that I was going to avoid the disease somehow. Now I’m scared and worried. I’m thinking only about the things I won’t be able to do anymore.”
3. Type 2 diabetes is a very common disease and requires treatment of blood sugar, blood pressure and blood lipids

Patients with type 2 diabetes are often overweight, have raised blood pressure and impaired lipid metabolism. Most of them die from cardiovascular diseases, and often have diabetes related kidney, eye and nerve damage and leg impairment. In addition to raised blood sugar, it is necessary to treat high blood pressure and raised levels of lipids because they contribute to the development of diabetes complications. Patients with type 2 diabetes are also likely to have mental disorders.

From the moment of diagnosis, patients with type 2 diabetes need an intensive care of the raised levels of blood sugar, pressure and lipids. We want to achieve the set goals quickly and safely.

The basis of the treatment, encouraged through the entire life, is healthy lifestyle.

**Education empowers patients to manage their disease independently.**

Patient education on managing diabetes is a lifelong process. It needs to be accessible to patients upon the diagnosis of diabetes, at each change of the treatment, in regular time intervals, upon patient’s request or upon the initiative proposed by the healthcare team. It must offer patients important and clear messages that will help them take care of their disease independently and in a best possible way.

All medical professionals working in the team must have adequate knowledge and skills to carry out education.

The healthcare team includes a doctor, a nurse or an educator and other profiles regardless the level of medical care. Patients and their family and friends are equal members of the team.

The indicators of diabetes regulation are determined with standardized methods that must be accessible.

By measuring the concentration of blood sugar (glucose), we determine only the current state. Therefore, to measure the medium-term regulation of blood sugar, which reflects the regulation of glycaemia in approximately the last two months, the method of determining glycated haemoglobin (HbA1c) is used. Another very important criterion of blood sugar regulation is the self-control of blood sugar, carried out by patients at home. For this, they need medical devices that must be accessible and of quality. The accessibility of adequate education and the motivation of the patient for the treatment are equally important.

We encourage the accessibility of new and safe medications and techniques of proven effectiveness in treating type 2 diabetes.

The condition for effective, safe and equally accessible care for all patients are professional guidelines and clearly defined and established clinical pathways.

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**SLAVKO, 57 years old**

“I’ve been type 2 diabetic, recognised in 1994. My diabetes was treated with several types of anti-diabetic drugs, and from 2004 I was on a combination therapy. Despite all that I wasn’t successful in controlling my diabetes. I also had raised blood pressure and raised levels of cholesterol. It became clear to me that I couldn’t go on like that anymore. What was I to do? I started following five basic principles: regular daily physical activity, balanced diet, optimal body weight, personal responsibility and self-control. This is my style today, which has improved the quality of my life and I can only say: I control diabetes, it doesn’t control me.”
The organisation of care provided to patients with type 2 diabetes must enable equal, quality and safe care regardless which level of healthcare system it is being carried out at.

The community pharmacist is the most accessible medical professional and can make important contributions to provide better care to patients with type 2 diabetes.

Effective and quality care provided to patients with type 2 diabetes is based on qualified medical professionals, good circulation of information about the patient and continuous communication and possibilities for consultations among different medical professionals.

4. Type 1 diabetes: patients can imitate functions of the pancreas with their actions

Type 1 diabetes occurs because of a complete destruction of the insulin-producing cells of the pancreas. The disease cannot be prevented and is incurable. Immediate insulin treatment is required upon the diagnosis. Departure from the treatment will result in death. The incidence of diabetes is growing by the year and at the same time, the number of patients having this type of diabetes is also increasing. This type occurs more often in younger generation, most frequently in children and adolescents.

The purpose of the care provided to patients with type 1 diabetes is a quality, full and unabridged life with as little restrictions as possible. That is why education is very demanding.

Patients with type 1 diabetes need to have a lot of knowledge; they must master many skills and be highly motivated for self-care. They must be skilled in decision-making and must trust the reliability of their own decisions. They must know the basics of metabolism and content of foodstuffs. They must know how to estimate the content and the type of carbohydrates in foodstuffs and adapt the insulin dose accordingly. The goal is a normal blood sugar along with still acceptable risk of hypoglycaemia.

During the medical treatment of type 1 diabetes we are faced with constant development of methods for the management of diabetes.

New and new types of insulin and new systems for self-control of blood sugar and for the application of insulin are available. New methods of treatment, such as cell transplantation, are being tested.

Family members and others close to them are included in the care of the patients with type 1 diabetes. Peer educators and other non-professional consultants can provide assistance to patients and the people close to them to persevere with effective management of self-care.

Family members and other people close to the patient or those who are having regular contacts with the diabetic such as schooleachers are included in the process of providing care to children with this type of diabetes.

The care should ensure early detection of complications and their quality treatment.

Twenty years after the emergence of type 1 diabetes, 80 per cent of patients have diabetic retinopathy, and thirty years after the emergence of type 1 diabetes, the diabetic retinopathy occurs in almost every patient. Thirty years later one in two patients have diabetic kidney disease. The risk of getting cardiovascular disease is forty times higher in patients with diabetic kidney disease.

ANDREJ, 27 years old

“Simona was born in a completely normal way. She got diabetes when she was 18 months. Definitely, the biggest shock parents can experience is if their child gets ill. My wife and I were familiar with diabetes, so we knew that she would have to use injections for the rest of her life. We’re still not able to come to terms with it. The only one who has somehow accepted the disease is Simona herself, while we still haven’t. We are thinking about all the problems our daughter will have to deal with when she would want to try different things. And about her children, if she would like to have them one day. These are all the consequences.”
All patients who developed diabetes in their childhood or adolescence are treated in paediatric diabetes outpatient clinic. All patients must be ensured linear transition into the process of receiving care that is appropriate for adults. Patients who get diabetes as adults are led by healthcare teams at the secondary level of healthcare.

The organisation of detecting diabetes and care provided to patients with type 1 diabetes is less of a challenge due to a smaller number of patients and sudden clinical presentation, whereas treatment and education are very demanding and complex. During the transition from adolescence into adulthood, these patients need all the more carefully planned care.

5. Diabetes complications: stroke, heart attack, kidney failure, blindness, amputation

After years of exposure, diabetes can damage different organs in the human body. Damage to organs occurs because of the damage to the blood vessels that are providing them with nutrients. Macroangiopathy (a disease of the greater blood vessels) is a disease process, whose basis is atherosclerosis. The clinical picture depends upon which blood vessels suffer the most damage and is manifested as stroke, heart attack, angina pectoris and as narrowing (stenosis) of large arteries, which causes problems while walking, and gangrene, which can result in the amputation of a lower limb. Macroangiopathy (a disease of the greater blood vessels) is a disease process, whose basis is atherosclerosis. Particularly, it can damage kidneys, eyes and the nervous system. These diseases are referred to as diabetic kidney disease (diabetic nephropathy), diabetic retinopathy and diabetic neuropathy. One of the complications is often mental disorders. The importance of proper dental hygiene and of the care for the health of the oral cavity is often overlooked during process of providing care to patients with diabetes.

Complications of diabetes are an important cause of falling ill and early death and can impair the patient’s quality of life. Medical treatment of diabetes complications represents the biggest financial burden in providing care to patients with diabetes and is therefore directed into preventing these complications, their early detection as well as immediate, quality, effective and safe treatment.

Complications can be prevented by leading a healthy lifestyle and by managing raised blood sugar, pressure and lipids. A comprehensive care of all listed conditions is very demanding in terms of the content, implementation and organisation.

The preparation process of professional guidelines for providing care to patients with diabetes includes doctors from different medical specialties, other medical professionals and a diabetologist. The next challenge is to overcome the gap between knowledge and daily clinical practice. Due to huge organisational and financial burden, we need to be effective in the use of resources.

Different branches of medicine and other medical professionals are participating in the preparation and implementation of professional guidelines and clinical pathways and in integrating organisational structures.

In addition to family physicians, diabetologists and educators who provide the basis for care delivered to patients with diabetes, the following professionals are included in the prevention and the care of complications if needed: hypertension experts, lipidologists, cardiologists, angiologists, nephrologists, ophthalmologists, physiatrists, infectious disease specialists, cardiovascular surgeons, surgeons for surgical infections, occupational and sports medicine specialists, psychiatrists, psychologists, community pharmacists and many other medical specialists.

GREGA, 47 years old
“She asked me tons of questions, but she didn’t ask me about my sexual problems. I think the young female doctor was embarrassed.”
In the case of occurrence of any complication of diabetes, patients need additional support from their healthcare team; an important support can also be provided by other health professionals, the peer educators and other non-professional educators and members of different associations of patients and other non-governmental organisations.

The complications of diabetes can impact the patient's physical and mental health. In addition to treatment of these complications and rehabilitation, patients also need psychological support from health professionals and other people qualified to provide such assistance.

In order to successfully plan and implement patient care regarding the diabetes complications, it is necessary to know and monitor the incidence and prevalence of such complications.

Adequate treatment of blood sugar must be ensured also in the parts of the healthcare system whose activities do not concern diabetes specifically.

In some clinical situations, such as treatment in the intensive care unit, adequate treatment of blood sugar results in a significantly better outcome.

Cardiovascular disease in patients with diabetes normally has worse progression than in those patients who do not have diabetes, and can manifest atypically. For their recognition and treatment, all verified diagnostic and therapeutic possibilities must be fully taken advantage of.

Diabetic kidney disease can be detected early with regular blood and urine tests. Early medical treatment can decelerate the progression of diabetic kidney disease. As the kidney function declines, it is necessary to detect and treat the accompanying complications early.

In the event of final kidney failure, patients need one of the following forms of replacement therapy: haemodialysis, kidney transplantation or less often peritoneal dialysis. All the way from the first signs of diabetic kidney disease to replacement therapy, it is necessary to monitor the patient regularly and to adapt several elements of the self-care management. It is extremely important that health professionals give psychological support to patients, and it is also necessary to encourage their integration into associations of patients with diabetes and associations of patients with kidney disease.

An early detection and treatment of diabetic retinopathy and related complications helps to maintain the patient's vision.

Regular examinations of the fundus of the eye with fundus imaging are necessary for early detection and timely referral to the treatment. When vision starts to deteriorate, patients and the people close to them need to be offered support in the treatment process and be advised to take part in activities organised by associations of patients with diabetes or with visual impairment.

Diabetic neuropathy needs to be detected at an early stage, particularly the forms with the loss of foot protective sensibility, which is the most common cause for ulcers in the leg and can lead to amputation.

**FANI, 72 years old**

“32 years ago nobody told me about damages to the eye and kidneys. After 20 years of living with diabetes, I started having problems with my vision and kidneys. Gradually my vision began to fail. I can’t see anything for about a year now. Complete darkness. The state of my kidneys: At my regular blood and urine tests, doctors found out that my kidneys were slowly failing and they had stopped working properly. Eight years later I was still able to urinate but soon after my kidneys stopped working. Since then, I've been having dialysis four hours a day three times per week. Blood vessels in my legs are quite ok; my blood circulation is also fine. I can walk normally, the only time I have burning feet is at night.”
By determining the risk level of tissue damage, education and other preventive measures, it is possible to prevent complications in the feet. Different specialists must be included into the team providing treatment of diabetic foot. The core of the team are the physician diabetologist and a nurse with additional knowledge in the area of providing care to patients with diabetic foot, both of which collaborate with the patient’s family physician, the surgeon for surgical infection, the angiologist, the vascular surgeon, the orthopaedist, the physiatrist and other health experts. The treatment of painful polyneuropathy often necessitates the inclusion of neurologists and pain relief specialists in the care of the patient. Strong psychological support is often needed as well. Urologists are included in the treatment of erectile dysfunction.

Patients with diabetes, in particular those with complications, suffer from mental disorders more often.

The effect of diabetes on the patient’s mental state is still not quite clear. Children that develop diabetes before the age of five are prone to behavioural disorders. Adult patients have more problems with memory than their peers who do not have diabetes. The most common mental disorder in patients with diabetes is depression, which is two to three times more common compared to the population in general, but still comparable in terms of numbers to the patients with other chronic diseases. It occurs in approximately 30 per cent of patients. Anxiety is twice as common as in the general population; phobias are significantly more common as well. The following three complications are related to mental disorders most commonly: diseases of the large blood vessels (macroangiopathy), diabetic foot (damages to the blood circulation and nerves of the foot) and diabetic retinopathy in its advanced proliferative form. Particularly in younger female patients, anorexia and bulimia are more common.

Periodontal diseases and diseases of the oral cavity are more common in patients with high blood sugar levels. Treatment of periodontal diseases protects teeth and improves blood pressure regulation.

An inflammation of periodontal tissue (periodontal disease) related to insufficient and irregular cleaning of teeth is more common in patients whose raised blood sugar has been present for a longer time.

6. Self-care means that patients are empowered to manage their diabetes

Diabetes is a heavy burden for the patient. It often occurs together with high blood pressure and raised levels of lipids in the blood. More than 80 per cent of the patients are overweight or obese. The treatment of these states is extremely complex and cannot be based only on considerably rare visits of the patient to healthcare facilities. Active role of the patient is vital and the patient must become equal members of the healthcare team. In order to achieve as good results as possible, the patient has to be skilled and willing to accept diagnostic and therapeutic decisions in his every day life. He or she must know how to use medical devices such as blood sugar and blood pressure meters. The patient must know how to evaluate the measured levels and to make decisions based on the results. He or she has to precisely understand the nature of the disease, the importance of a healthy lifestyle and of losing weight.

The healthcare team must provide patients with clear and credible information about the diabetes and accompanying disease states in timely manner. Together, they must establish an appropriate attitude towards the disease and plan the care, in which the patient will have the central part. The team must also provide psychological support.

All these tasks of the healthcare team are incorporated in the expression “diabetes patient education”. The goal of everyone participating in the education process is a motivated patient who daily takes optimal decisions, important in the treatment of diabetes: This is called “patient empowerment”.

MINKA, 59 years old

“They say I have diabetes. I’m not too sure I will know how to prepare the right food, as I’ve been cooking my own way for all my life. So, shall I now cook one type of food for me and another for everybody else?”
Diabetes patient self-care includes a comprehensive co-operation in the process of the treatment of diabetes, a co-operation in the treatment of raised blood pressure and lipids, taking care of early detection of chronic complications, a comprehensive treatment of complications when they appear and taking care of one’s general health condition. Tasks of the healthcare system are effectively complemented by the people close to the patient, by associations of patients with diabetes and by other non-professional advisors.

In their daily self-care, the patient with diabetes makes the majority of decisions by himself or herself, without direct contact with the healthcare system.

The healthcare team should offer patients a safe environment that does not judge their actions, but directs him or her to make the decisions that will lead to the set goal.

Patients have different options and capabilities to participate in self-care, which is taken into consideration when formulating the treatment plan.

Co-operation of family and friends in managing diabetes can be of great help to patients, so they are included in the care when appropriate. When patients cannot handle the medical treatment by themselves, co-operation of family and friends is indispensable.

A comprehensive self-care is considered as patient’s self-management of blood sugar, blood pressure and lipids, the care for detecting diabetes complications and their treatment and the care for their general state of health.

With self-control, by measuring blood sugar at home, patients can control the success of the medical treatment of diabetes on a daily basis. For these measurements, they need reliable and simple medical devices that should be as accessible as possible. On the basis of the measured values of blood sugar, patients can adjust their meals and physical activity or alter the doses of insulin. All these patient activities are called blood sugar self-management. Self-care includes not only the self-management of blood sugar but also encompasses the self-management of blood pressure and lipids, the care for detecting diabetes complications and their treatment and the care for the general state of health.

Educating patients with diabetes is an integral part of providing health care and is one of the basic activities of healthcare teams. Due to the complexity of education, members of healthcare teams need numerous additional and special proficiencies.

In structured education programmes that are intended for different contents and groups of patients, group and individual education are interwoven and complement each other.

Education must be available to patients upon the diagnosis of diabetes, at certain turning points in the course of the disease (for example at the start of the insulin treatment), during regular periodical evaluations of self-care and upon patients’ request.

The education assessment is a process where we are looking for more effective education programmes, methods and skills.

The effectiveness of education can be measured in terms of reaching the goals of the treatment of diabetes (the control of blood sugar, pressure and lipids) although these indicators are not the only ones that are important. An assessment of the education must include indicators of the system’s circulation, indicators of the patients’ satisfaction with the provided care and their quality of life in terms of diabetes and indicators of satisfaction of other members of the healthcare team.

**KAREL, 68 years old**

“30 years ago when I was diagnosed with diabetes, the only thing that was known about diabetes was that you were not allowed to eat sugar. I can say that I also knew very little about the disease. An education process is needed to learn how to react in a particular situation. Many very diverse factors can impact the blood sugar.”
Team planning of care strengthens patient’s stability and perseverance in self-care and maintains patient’s internal motivation.

Structured education and team planning of care are based on professional guidelines. Equal accessibility is ensured with clinical pathways and adequate resources needed for the education.

Physicians, educators, nurses and other medical professionals need to be educated and trained in psychological skills, communication skills and techniques of children and adult teaching.

An adequately educated patient with diabetes, named the peer educator, or other non-professional advisor can support other patients to persevere in a successful self-care of diabetes.

In their health care, patients answer to themselves and the healthcare system. They treat the available resources responsibly. They actively search the options to purposefully and effectively use the available resources.

The diabetes complications will be prevented or delayed by adopting a healthy lifestyle.

Healthy lifestyle is the basis of the treatment of diabetes. Regular physical activity improves metabolism, has beneficial effects on blood sugar, blood pressure and the levels of lipids in the blood and helps to maintain appropriate weight. Healthy eating habits have beneficial effects on all risk factors for the complications of diabetes.

Changes to the lifestyle represent great challenges to patients with diabetes, so they are planned in small steps, and in collaboration with patients.

Education on special requirements regarding lifestyle is always needed alongside the treatment with insulin or drugs that increase the release of insulin from the pancreas.

With unequal intake of carbohydrates or changes to metabolic processes because of physical activity, both groups of medication can cause the blood sugar to drop to low - this is called hypoglycaemia. Patients must identify this state and act correctly because the situation can worsen to the extent of becoming dangerous.

JOŽI, 60 years old

“I’ve had diabetes for 10 years. I was sticking to my diet, I was exercising regularly and I was walking quite a lot. But I still needed tablets. Then I started to strictly watch my calories and I was able to lose weight. Although I’m still taking tablets, my blood sugar is regulated. When tablets won’t be enough anymore, I’ll need insulin. Insulin is actually my ally; the only difference being that I will have to stick myself with needles.”
7. Diabetes and pregnancy: let’s protect the child and the mother

We are faced with pregnancy and diabetes when a patient with diagnosed type 1 or type 2 diabetes becomes pregnant or we discover diabetes during pregnancy, which is called gestational diabetes. 0.2–0.3 per cent of pregnant women have diabetes before becoming pregnant, whereas 3–5 per cent of pregnant women develop diabetes during pregnancy. Diabetes is therefore one of the most common disease states that endanger pregnant women and their children and increases the risk for developing complications during pregnancy and in the child.

Patients with diabetes in a fertile age need meticulous care. The end of pregnancy in women with diabetes that was present before they became pregnant depends on the control of blood sugar at the time of conception and during the course of the pregnancy as well as during perinatal and neonatal care.

Pregnant women without diagnosed diabetes before the pregnancy can develop gestational diabetes. It can be detected in time only with a screening test because this type does not cause any problems that would point to diabetes. Gestational diabetes that is not treated or is treated poorly can cause excessive fetal growth and can increase the risk for delivery injuries. In addition, overweight newborns are at high risk for obesity and type 2 diabetes later in life.

Patients with diabetes during pregnancy need consultation on planning the pregnancy at least once a year, and be advised on contraception when needed. Even in the period before the planned pregnancy, women need directed education and care that includes the patient, a diabetologist, a gynaecologist perinatologist, an ophthalmologist and an educator.

In all pregnant women who are not diagnosed with diabetes before the pregnancy, we assess the risk for developing gestational diabetes and based on the risk, we make screening tests for detecting diabetes. The estimation of the risk for developing diabetes and the screening test are a part of regular care provided in a gynaecological clinic. Care during pregnancy is the same as in patients who have had diabetes even before the pregnancy.

Women with gestational diabetes are at high risk for developing type 2 diabetes so they get included in the programme intended for persons at high risk for developing type 2 diabetes.

PETRA, 31 years old

“During my first pregnancy, only my general practitioner diagnosed me with high blood sugar, and my baby boy had 4.5 kilos and the labour itself was difficult. During my second pregnancy, my gynaecologist measured my blood sugar right away and gave me instructions for my general practitioner about controlling my blood sugar and pressure. I was very excited about my pregnancy. Then, I found out that I had raised blood sugar. I was paralysed by the fear for my baby! From the sixth month into my pregnancy, a diabetologist took care of me and my blood sugar was measured each month. From the eight month onwards I was on insulin, I had regular check-ups once a week and I also visited a gynaecologist for diabetic women. My baby girl was fine. After the delivery the ward staff couldn’t measure my blood sugar so it was measured by my husband. Everything was alright, I don’t need insulin anymore, but I’m fully aware that diabetes can come back.”
8. Managing diabetes in children and adolescents is an investment into the society’s future

Diabetes in children, adolescents and young adults is very different from diabetes in adults. 90 per cent of patients with diabetes in the age group of under 25 are diagnosed with type 1 diabetes and only 10 per cent have type 2 diabetes. An important fact is that the prevalence of type 1 diabetes in this age group has been increasing by four per cent per year in the last few decades. Due to unhealthy lifestyle and obesity, type 2 diabetes is becoming more prevalent among the younger population.

Early development of diabetes in children, adolescents and young adults means that this group is at a particularly high risk for an early development of diabetes complications that, in addition to the known increased risk for cardiovascular diseases, damages of the eye fundus, kidneys and nerves, encompasses also increased risk for a decline in the cognitive function and permanent brain damage. Therefore, these age groups must receive the best possible care and treatment. It is also important to provide young people with diabetes with equal integration among their peers. Hereby, the pre-school and school environment must participate together with their parents.

Type 1 diabetes is increasing among children, adolescents and young adults so care is being adapted to their growing up. Modern technology facilitates the treatment of the disease and supports a life of higher quality.

According to the latest data, the prevalence of type 1 diabetes in this age group in Slovenia has surpassed 12/100,000 inhabitants per year, which puts us among other Central European countries where the prevalence is about the same or slightly higher. The disease is the most common during puberty and has been quickly increasing among pre-school children in the last few years. Because the cause of decay of beta cells of the pancreas is mostly caused through autoimmune mechanisms, the disease cannot be prevented or cured for the time being. Precise insulin replacement along with continuous and regular blood sugar measurements remains the sole way of treatment.

Providing care to young people with type 1 diabetes is always a teamwork. The team includes a paediatrician diabetologist, a graduated nurse educator, a dietician, a psychologist, a registered nurse and a social worker and other specialists if needed. The young person with diabetes and his or her family co-operate in the team equally and in the education process contribute to decision-making on the most appropriate approach in managing diabetes. As the young person grows and develops, the disease management strategy needs to be dynamically adapted to new circumstances, in particular to changes at home and at school and have to prepare the person for the transition to the environment of diabetology.

The use of modern technology is crucial for a successful management of diabetes. The use of insulin pumps and sensors for continuous measurement of glucose has major clinical impact on the success of diabetes regulation and significantly reduces the prevalence of a dangerous lowering of blood sugar – hypoglycaemia. Research results have also shown that the use of the technology significantly improves the quality of life of young people with diabetes and their families. This is why it is necessary to ensure accessibility of quality technology to all young people with diabetes.

JAN, 12 years old

“I developed diabetes when I was eight and a half. The first two signs were raging thirst and constant peeing. Because these signs were getting worse, my mom asked a family friend to measure my blood sugar in a joke because she didn’t know what could possibly be wrong with me. After he measured my blood sugar, there was dead silence in the house. I had more than 30 millimoles of sugar in my blood. After we got over the initial shock, we decided to go to the school doctor immediately to get help.”
Type 2 diabetes in children, adolescents and young adults needs to be detected early. Structured actions delay its recurrence or can even prevent it.

With the growing problem of obesity, less and less physical activities and unhealthy eating habits, based on excessive intake of cheap foodstuffs high in carbohydrates, the prevalence of type 2 diabetes has begun to increase among the young. Type 2 diabetes is more common in socially weaker families where parents have lower education, lower income and live in a worse living environment. Therefore, type 2 diabetes in young people can be categorised as a social disease of the modern society. In addition to the mentioned above, a genetic predisposition, which is normal to low in the Slovenian population, plays an important role in the development of type 2 diabetes.

Selective screening of all young people meeting the criterion of obesity is carried out as an age-adapted oral glucose tolerance test. In this way we can detect all stages in the development of type 2 diabetes in time.

The management and treatment of type 2 diabetes in young people always starts by changing lifestyle. This step involves a psychologist who significantly participates with behavioural and motivational approaches at the level of the entire family and a dietician who is also of crucial importance. A success in changing lifestyle can through losing weight to normal levels perhaps completely cure the developing type 2 diabetes.

The co-operation of the entire family is necessary to prevent obesity in children, adolescents and young adults.

Slovenia has developed a well-organized network of primary paediatrics which by regular medical check-ups of schoolchildren and general following of the young population detects early whether the children are overweight or obese. It is vital to ensure the co-operation of the school system at all levels, the co-operation of experts on physical activity, the co-operation of media experts and a co-ordinated cooperation of the entire society that must adopt adequate acts and implementing regulations for providing comprehensive activities. Regarding this, Slovenia falls behind many EU countries, particularly in the area of regulation since advertising of extremely unhealthy foods and drinks to children is unfortunately still very much present on a regular daily basis.

**NIK, 23 years old**

“I watch my friends, we know each other from the Pediatric Clinic where we went because we had diabetes, and I wonder at what age patients should start visiting a diabetologist for adults. When one is a child, the treatment and education is on the parents’ shoulders. Only when I started going to a diabetologist for adults I realized that I needed to know a lot about diabetes, I needed to know how to measure blood sugar, my diet, complications etc. It was different.”
9. Monitoring the quality of care is a basis for its continuous improvement

The quality of care is monitored at the level of individual patients, individual healthcare units involved in providing care, at the regional level and at the national level. Monitoring the quality of provided care at the level of individual patients helps in assessing long-term patient care, in preparing annual reports and in the planning of care. Monitoring the quality of care at the level of individual units of the healthcare system enables an evaluation of its effectiveness and of introduced changes in terms of content and organisation. At the regional level it enables the comparison of the results of provided care among different units and ensures feedback information to the providers of healthcare, which serves as the basis for planning future improvements. By monitoring the quality of care at the national level, we can plan systemic changes where needed and evaluate their effectiveness. The data for some indicators of quality of care regarding diabetes, which are known to about half of the EU member states, also enable international comparisons.

- Monitoring the quality of care provided to patients with diabetes is incorporated into the healthcare system.

- We also need uniform criteria of determining the quality of provided care.

The chosen indicators of quality of care should reflect how well the goals of treatment of blood sugar, pressure and lipids are being achieved as well as the presence of diabetes complications. It will be we necessary to include adequate number of process indicators (indicators of accessibility, safety and effectiveness) and indicators showing the balance of the system (e.g. balanced accessibility to all education programmes) among the criteria of the quality of care.

- Legal basis should support the monitoring of the quality of the provided care.

The system must ensure reliable patient identification, personal data protection and reliable protection from abuse.

10. Organising the care of patients with diabetes encompasses all levels of the healthcare and extends beyond the healthcare system itself

The responsibility of the Ministry of Health is to develop, implement and monitor the strategies of the healthcare system, which also include diabetes management. The Ministry will establish a working body that shall monitor and encourage activities aimed at implementing the national programme at the national level. In order to be able to implement the planned activities at the local level, we will have to establish regional working groups for the integration of activities regarding diabetes management, which will function as coordination bodies with specific responsibilities and competencies.

- ANJA, 44 years old

“It meant a lot to me to get the feeling that nurses and doctors were really interested in my condition and that I was important to them as a person.”
Such a group must represent the physicians of family medicine, diabetologists, educators on a primary and secondary healthcare level, pharmacists and patient associations, it must also cooperate with different other profiles that are actively participating in the organisation of care such as community nursing service, outpatient clinics of occupational and sports medicine, school medicine, gynaecology, retirement homes and other social security facilities, kindergartens, schools, faculties, media and others.

The care of patients with diabetes is the task of the healthcare system. Division of areas of work among the levels of the healthcare system must be clearly defined. The manner of financing must encourage effective and rational care at all levels of healthcare.

The healthcare team providing care to patients with diabetes includes a doctor, a nurse or an educator and other professionals regardless of the level of healthcare. The patient is an equal member of the team and co-creates the joint care plan.

The organisation of comprehensive care must encompass all elements of complex care.

The organisation of comprehensive care encompasses effective treatment of raised blood sugar, pressure and lipids, early detection of diabetes complications, enables immediate and intensive treatment of these complications and ensures the development of all rehabilitation potentials.

Regarding the use of financial, human and others resources, the care of patients with diabetes is very demanding. The care for effective use of there resources is necessary for the sustainability of public healthcare system.

Due to their disease, patients with diabetes can find themselves in unequal position. Healthcare system should therefore link with other key stakeholders in the society to ensure greater social security of patients with diabetes.

In Slovenia, there are local differences in the organisation of providing care to patients with diabetes.

In implementing changes in the organisation, it is important to derive from the existing state, to introduce changes carefully and to keep all those elements that ensure quality care with special care.

Healthcare system must ensure accessibility, circulation and care based on professional guidelines.

Care of patients with diabetes is complex, life-long and is intended for a large number of patients, so it requires connecting of partners within and outside the healthcare system.

Partners that can make considerable contributions to a comprehensive patient care may also be organisations of occupational and sports medicine and social security institutions as well as patient associations and other non-governmental organisations. In the care of patients with diabetes, pharmaceutical companies can be useful by carrying out non-promotional activities.

Coordination of care at the local level is performed by regional working groups, which include the participation of patients alongside medical professionals.

KIRSTINA, 64 years old

"I'm confused. The nurse tells me one thing, the doctor another, my neighbour who's always on the Internet something else."
11. Research related to diabetes management spreads into many areas, so constant co-operation is needed

Research activities regarding diabetes management include research in the area of diabetes prevention and in the area of providing care to patients with diabetes. It must be implemented on all levels of healthcare and outside the healthcare sector and can include research in the area of public health, health economics, quality physiology, medication and medical devices, behaviour and patient satisfaction.

The complexity of measures in controlling diabetes requires interdisciplinary research, which means that constant linking and co-operation between research groups and institutions is essential.

Ensuring resources for research is often insufficient although the requirements for research excellence are high.

Patients are important partners in research activities, so it is necessary to raise awareness among patients with diabetes about the significance of research activities.

Results of the research activities must be translated into practice as soon as possible, especially when they enable better prevention and diagnosis of diabetes as well as providing better care to patients in terms of quality and effectiveness.

12. Education and raising awareness of medical professionals and persons without medical education enable better effectiveness of diabetes management

In providing care to patients with diabetes, there is interaction between doctors of different specialties, educators and other medical professionals and other professionals that can contribute with their actions to providing better patient care in the period between individual healthcare treatments.

All healthcare and non-medical professionals as well as lay persons that are included into the care of patients with diabetes need specific proficiencies in the area of diabetes that have to be constantly upgraded.

Co-operation of adequately educated lay consultants and other persons that can make important contributions to providing care to patients with diabetes has a special significance.

SONJA, 38 years old
“During education I often see the distress of patients and of their family and friends. What they particularly need is for me to listen to them and tell them some small but true words.”

SLAVKO, 57 years old
“Diabetes cannot be cured but it can be controlled.”
Together in reducing the burden of diabetes

13. Patient associations and other non-governmental organisations are taking on an important role in diabetes management

In accordance with the Strategy of Cooperation of the Government of the Republic of Slovenia with Non-Governmental Organisations from 2003, an important partner in formulating and implementing the Programme are patient associations and other non-governmental organisations that with their interests and modi operandi can make significant contributions to diabetes management and encouragement of healthy lifestyle in general. The area of their work is mainly to encourage healthy lifestyle, to provide an active and continuous support to patients with type 1 and type 2 diabetes and a help in the process of education and raising awareness of patients with diabetes, their families and friends and persons at high risk for developing type 2 diabetes and to defend the interests of patients with diabetes.

Patient associations and other non-governmental organisations are making important contributions to life-long education and raising awareness of the patients about the diabetes self-care.

Patients who are experienced in self-management and self-care of diabetes and who can help with their knowledge and example to patients and their families and friends in the self-management of the disease or in changing their lifestyle can have an important role as peer educators.

Patient associations and other non-governmental organisations encourage healthy lifestyle and educate and inform about different ways of preventing type 2 diabetes. Their activities are intended for those that are at high risk for developing type 2 diabetes as well as for the general population.

Patient associations are publishing journals such as Diabetes (“Sladkorna bolezen”) that are accessible to patients with diabetes and wider public. They are also using modern information technology (for example, the website of the Slovenian Diabetes Association).

Patient associations and other non-governmental organisations represent the interests of patients with diabetes.

SREČO, 52 years old

“Patients sometimes need time. I understand that doctors and nurses don’t have that time. And that is why meetings with other patients with diabetes mean so much to me.

BRANE, 47 years old

“At the stand of the diabetes patient society I have been measured blood sugar and the result was 17.3 mmol/l. They referred me to my family physician for a follow-up examination where it was confirmed that I had diabetes. Three months later I entered the society of patients with diabetes. I was glad that they measured my blood sugar and advised me to go to the doctor. I will change my lifestyle, I participate in the society’s lectures and workshops. I’m actively participating in the society where we are exchanging our experiences with diabetes.

JANA, 53 years old

“I was relieved when I met other patients. You see that you are not the only one with these problems because others have similar issues. You can ask them how they have overcome these problems. And you can help others with your experiences.”
14. Monitoring and coordination of the implementation of the Programme ensure its success

The realisation of the programme's goals has to be monitored and evaluated constantly, while the taken measures need to be adapted to new scientific discoveries and experiences regarding the efficiency of individual measures.

To be able to ensure coordination and monitoring of the realisation of the programme's goals, the Ministry of Health appoints a coordination working group that will prepare annual reports about how successful is the implementation of the programme, which will serve as starting points for future biannual action plans. At the end of the Programme in 2020, the coordination working group shall prepare a final report which shall include the evaluation of the implementation of the Programme and on the basis of the report and the evaluation it shall submit a proposal to the Government of the Republic of Slovenia regarding future measures.

Representatives of the ministry, the profession, the civil society and the Health Insurance Institute of Slovenia shall be appointed into the coordination working group.

One of the key tasks of the coordination working group is to monitor and take part in the processes within and outside the healthcare system that are important for diabetes management such as setting up the healthcare information system and encouraging partnership in the implementation of the programme.

15. Partnership is based on trust and finding mutually agreed solutions

A comprehensive approach to controlling diabetes as one of the most important chronic non-communicable diseases requires co-operation between different sectors and institutions.

For the Programme to be successful, it is necessary to ensure synergy in the co-operation of all partners that must be based on shared values and goals, mutual trust, complementing, the search for mutually agreed solutions and the sharing of results.

It is impossible to imagine the realisation of the programme’s goals without including patients in the process of planning and implementing all activities in the area of controlling diabetes.

FRANCI, 71 years old

“Sometimes it is really hard to go to a medical check-up. You come to people who are supposed to help you and support you…. The last thing you need is to be told over and over again that you’re again doing something wrong. Sometimes I feel humiliated and scared… Sometimes I don’t even ask if I don’t understand certain things, because I’m afraid to ask…"

MARTIN, 62 years old

“Patients with diabetes want the best possible medical treatment regardless who we are or how severe our disease may be. You have to realise that without our cooperation in the process of treatment we are only wasting time. Try to help us understand diabetes to the best of your abilities and take into consideration how important our co-operation actually is. Help us to be able to co-operate in the treatment of diabetes for the rest of our lives. Lend us your hand when we’ll throw in the towel because we certainly will. Treat us like people and not like a condition."
LONG-TERM PROCESSES FOR ACHIEVING GOALS OF THE PROGRAMME

We have identified four key horizontal processes for meeting the challenges of the Programme that will be a permanent feature of the implementation of the Programme and represent a wider framework of the action plan:

• patient empowerment;
• coordinating the healthcare system between different levels, individual professional fields and within the healthcare team
• monitoring diabetes management and the implementation of the national programme and
• fostering partnership.

1. Empowering the patients

In their everyday life, patients with diabetes make most decisions regarding their disease by themselves. The goal of the healthcare team's activities is an empowered patient that makes the best possible decisions regarding his disease on a daily basis. An empowered patient is an equal partner in the team and constructively and responsibly participates in the process of planning and implementing the treatment of his or her disease. Patients gather in associations where they can actively contribute in ensuring better conditions for preventing and treating diabetes in individual patients, their families and friends and in the entire society.

An empowered patient is the best guarantee for a successful and permanent realisation of the programme.

2. Coordinating healthcare system between different levels, individual professions and within a team

Until 1991, diabetes patient care was organised in a type of community-based outpatient clinics (dispanzerji), organisational units within community health care centres. These types of clinics were mainly part of hospitals where they had specialists of internal medicine and nurses with additional proficiencies. In 1991, this type of diabetes clinics (diabetološki dispanzerji) were abolished as organisational units and were transformed into specialists outpatient clinics and at the same time diabetes patient care was transferred to the primary level of the healthcare. As a unified system of diabetes care was not established, different organisational forms have emerged in individual local communities according to their possibilities, with different care distribution among the primary and secondary level. At the system level, the distribution of care among primary and secondary level still has not been defined.

The diabetes patient care is implemented by a healthcare team. The development of the professional field shows that the roles of individual healthcare team members are changing, the team is expanding and the role of patients is becoming ever more important. In this respect, we need to change the activities of the existing healthcare teams on secondary level and to upgrade and establish teams on the primary level.

3. Monitoring diabetes management and the implementation of the Programme

In order to ensure monitoring of the progress in controlling diabetes, we need to prepare a proposal on how to establish the system which would ensure high-quality data that can be accessed already in the period of the first action plan. The system of monitoring diabetes is a part of a wider system of monitoring medical indicators, so it is necessary to take account of all the processes relating to this
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system. One of such processes is to monitor the quality of provided medical care which is necessary in the area of controlling diabetes in order to improve care and to achieve better results.

On the other hand, we need to ensure the monitoring of the programme's implementation from the beginning with adequate process indicators and result indicators that will be the basis for a regular evaluation regarding how the goals of the Programme are being achieved and for future planning. The proposal of the Programme monitoring system will be one of the first tasks of the coordination group that will be appointed by the Ministry of Health.

4. Fostering partnership

In order to effectively manage diabetes, we need to ensure coordinated work between different sectors, co-operation between all levels of the healthcare and inclusion of all key partners, in particular the patients and the civil society in general.

Cooperation between all relevant professional associations, the Ministry of Health and the payer is key to enable the development of the profession, better organisation and adequate financing of all activities. On the one hand, the connecting of partners is ensured by establishing a coordination group at the Ministry of Health and on the other, by ensuring smooth circulation of information between institutions, by ensuring opportunities to exchange information and good practices and by informing the public together.
CONCLUSION

As one of the chronic diseases, diabetes is linked to a great burden from many aspects. It represents one of the leading causes for morbidity and mortality with serious and direct economic consequences and the reduced productivity of the society. It affects all age groups and both the working and the living environments; it has also an impact on the patient's social environment. The incidence of the disease is linked to non-beneficial social and economic determinants of health as well as to risk factors of unhealthy lifestyle on the population level, which requires measures from the public healthcare system and cross-sectoral projects. The disease needs a lifelong care and is complex. Coordination of different medical professionals is needed and due to the connection with the lifestyle and psychological and social burden, its care extends outside the healthcare system and calls for the integration of the healthcare and the social system.

From the strategic point of view, we would like to decrease the growing burden of diabetes by prevention and early detection, by the introduction of new and upgraded roles of professional groups and by the creation of new working environments. We need to improve the coordination of providing care and to try to integrate the diabetes care with the care of other chronic diseases at all levels. In particular, we need to improve the areas of care coordination, communication, information circulation, the development of the culture of evaluating performance, effectiveness and safety, the development of financial incentives and procedures to introduce new drugs, devices and technologies. We will search for innovative and realisable solutions, which will take into consideration available resources and will be based on professional and financial sustainability. We will foster a shared vision that is written in this document.

For achieving our vision, our shared values of co-operation, respect and trust that have connected all the partners who helped to prepare this Programme, and the focal point of all deliberations, discussions and actions - the diabetic patient himself, are even more important than the document.

Therefore, we are all TOGETHER in reducing the burden of diabetes.
Together in reducing the burden of diabetes

COLOPHON

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