

CHARTER OF RIGHTS OF PEOPLE WITH DIABETES

The Parliamentary Association for
the Protection and Promotion
of the Right to Health



Associazione
Diabete Italia

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Diabetes Attitudes Wishes & Needs

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TABLE OF CONTENTS

1. The Rights of People with Diabetes
2. Expectations and Responsibilities of People with Diabetes and Their Families
3. Permanent Education of People with Diabetes
4. The Dialogue between Doctor and Person with Diabetes
5. Controlling Diabetes
6. Preventing Diabetes
7. Commitment to Research
8. Responsible Associations
9. Diabetes and Pregnancy
10. Diabetes in the Developmental Age
11. Immigration and Diabetes

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Diabetes Attitudes Wishes & Needs

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of the Right to Health



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PART ONE

THE RIGHTS OF PEOPLE WITH DIABETES

The rights of those who have diabetes are the same human and social rights of people without diabetes.

These rights include equal access to information, therapeutic education, diabetes care, as well as diagnosis and the care of complications.

The national healthcare system shall guarantee to people with diabetes, uniformly across the national territory, the use of appropriate diagnostic and therapeutic methods.

The right of people with diabetes to live a social, educational and working life on par with people without diabetes shall be considered the primary goal of government action.

1. **Supporting** people with diabetes and their families to overcome obstacles, prejudices and mistrust, through the use of information, training, educational and social instruments, with the assumption of responsibility and active contribution on the part of the institutions, the healthcare system, scientific societies and volunteer associations.
2. **Increasing** social awareness in schools, work places, sport facilities, healthcare facilities, and social organizations, so as to prevent personal and professional discrimination and preclusion.
3. **Training** healthcare professionals, school teachers, and sport trainers; raising awareness among colleagues on how to prevent, recognize and any treat emergency situation that might possibly arise.
4. **Asserting** that having diabetes does not prevent people from pursuing their goals on a personal level, in their family life, at work, or in sports and society.
5. **Ensuring** uniform access to the healthcare system across the entire national territory, so as to promote the best quality of care and life, as well as the prevention and treatment of the complications.
6. **Promoting** in all regions actions aimed at identifying people at risk, so as to ensure the early diagnosis of impaired glucose tolerance and diabetes mellitus.

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PART TWO

EXPECTATIONS AND RESPONSIBILITIES OF PEOPLE WITH DIABETES AND THEIR FAMILIES

People with diabetes and/or their family members are not always aware of the care path or of the long-term pharmacological and nutritional treatments, as defined by the current care guidelines.

People with diabetes and their family members might mistakenly think that the situation is “under control” due to the lack of symptoms and, therefore, they might suspend an adequate therapy or modify it improperly.

People with diabetes and their family members shall receive accurate information about the causes of decompensation and about the risk factors leading to the development of complications, so that they are aware of the importance of following a healthy lifestyle, in line with their possibilities and needs.

Therefore, the following is necessary:

1. **Educating** people with diabetes and their family members, so that they are able to live according to their aspirations.
2. **Helping** families manage diabetes by providing permanent training and information, instruments and services that take into account individual needs.
3. **Stimulating** healthcare professionals (specialists, GPs, nurses, psychologists, nutritionists, podiatrists, etc.) to actively listen to people with diabetes and their families, and, moreover, devote an appropriate quantity of time, so as to be able to understand patients’ needs, aspirations, and expectations.
4. **Persuading** healthcare professionals to explain the care goals, always checking that they have been understood, and to develop care plans (personalized, shared, explained both orally and in written form) which include indications on the treatment to be routinely followed, as well as on what to do in case of emergency.
5. **Inviting** all healthcare professionals to take care of the psychological and social aspects of people with diabetes and their family members.

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of the Right to Health



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PART THREE

PERMANENT EDUCATION OF PEOPLE WITH DIABETES

The permanent education of people with diabetes, their family members and their social context, is an indispensable instrument for a successful therapy, to prevent and recognize the complications that might possibly arise, and to attain full autonomy in the daily management of diabetes.

It is important to acknowledge the central role of educational therapy, by organizing structured courses.

Therefore, the following is necessary:

1. Training healthcare personnel and volunteer associations so that they are able to provide, respectively, therapeutic education and healthcare education to people with diabetes and their families, according to their specific clinical and socio-cultural needs.
2. Sharing with patients their care goals and choices after providing thorough information, so as to facilitate the management of diabetes in daily life.
3. Defining care, healthy diet and regular, personalized physical activity together with the patients.
4. Making use of complete multi-disciplinary teams featuring specific skills (medical, psychological, nutritional, nursing, social, etc.) that are useful to remove the barriers against correct diabetes management.
5. Ensuring uniform access to educational therapy across the entire nation.

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PART FOUR

THE DIALOGUE BETWEEN DOCTOR AND PERSON WITH DIABETES

In order to effectively manage diabetes, it is indispensable that the GP and multi-disciplinary team of reference not only understand the bio-medical aspects of people with diabetes, but also the psychological and social ones. As well, the perceptions, needs, and obstacles patients face should similarly be understood, as such elements ought all be integrated in the care plan.

Likewise, people with diabetes shall be given a context where they can express their opinions and relate their situation.

Therefore, the following is necessary:

1. **Persuading** healthcare professionals to establish a true care alliance with people with diabetes and their family members. Such an alliance should include: active listening, empathic communication, open dialogue and regular checks not only on the patient's state of health, but also on the quality of the service provided.
2. **Inviting** healthcare professionals to support people with diabetes in their acquisition of full awareness of their condition and treatments.
3. **Analysing** any habits and dynamics – of both the individuals and their families – which might promote dangerous behaviour.
4. **Increasing** access opportunities and the availability of contacts with healthcare professionals through complementary means of communication, such as the telephone and IT channels.
5. **Facilitating**, as much as possible, continuity in the relationship between the person with diabetes and the multi-disciplinary team at the diabetes centre, and checking if this also occurs through civic participation.

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PART FIVE

CONTROLLING DIABETES

People with diabetes should be aware of the chronic nature of their condition, which might be asymptomatic or display symptoms featuring varying degrees of seriousness, and should be enabled to manage their own care.

Correct management of one's diabetes makes it possible to go to school, have a job, have a social and emotional life, do sports, etc., like any person without diabetes.

Therefore, the following is necessary:

1. **Increasing** the knowledge of people with diabetes and their family members in regard to the treatments suitable for different clinical conditions. These treatments should be easy to carry out by the individual on his/her own, and enable effortless adaptation.
2. **Favouring**, during hospitalization in wards other than those specific to diabetes, the involvement of a diabetes specialist in therapy choices, or providing qualified diabetological assistance.
3. **Facilitating** the bureaucratic procedures for access to specific therapies and administration systems.
4. **Making** people aware that good control, in diabetes, also depends on regular physical activity, healthy diet, normal body weight, as well as the monitoring of blood pressure and dyslipidemia.

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PART SIX

PREVENTING DIABETES

There exist effective preventive measures which can be carried out in the general population, so as to reduce the onset of diabetes mellitus, thus limiting its huge impact on a personal and social level.

Institutions shall cooperate effectively with volunteer associations of people with diabetes and their families, in addition to scientific societies and civic organizations, with the aim of reducing the onset of diabetes among the population at risk.

Systematic and continual communication, aimed at favouring prevention and early diagnosis, makes possible the timely treatment of diabetes and the reduction of all its consequences.

Therefore, the following is necessary:

1. **Urging** local and national institutions to disseminate information and implement strategies for the prevention of diabetes.
2. **Informing** the population that it is possible to reduce the onset of type 2 diabetes by adopting a healthy lifestyle; prevention is also possible among people already at risk (adults and children).
3. **Involving** the institutions so that they allot appropriate resources to initiatives aimed at the prevention and early diagnosis of diabetes, through continuing and coordinated communication with scientific societies, volunteer associations of people with diabetes and their families, and civic organizations.
4. **Considering** family and school as privileged places to provide education on healthy lifestyles.
5. **Carrying** out health-related information and education programs in schools, sports associations, senior homes, and, in general, the community and workplace, by involving the healthcare authorities, the multi-disciplinary teams and the volunteer associations of people with diabetes and their families, in cases where they were established for this purpose.
6. **Inviting** extra-healthcare sectors (school, workplace, sport and community) and the media to disseminate a culture promoting healthy lifestyle choices.

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PART SEVEN

COMMITMENT TO RESEARCH

The investment in research, on the part of universities, healthcare institutions, the industry, public entities and scientific societies, represents a priority for the understanding, prevention and management of diabetes.

It is important that research be coordinated, in order to avoid the useless duplication of economic efforts; that it responds to the actual needs of people with diabetes, and that it also covers the fields of epidemiology, education and technological innovation.

Progress in the knowledge of diabetes and its care will make it possible to improve quality of life, prevent the onset of complications, reduce hospitalization and, subsequently, healthcare costs due to this condition, which is characterized by a high economic and social impact.

Therefore, the following is necessary:

1. **Increasing** communication between research entities and volunteer associations of people with diabetes and their families, in order to understand the real needs of people with diabetes and direct the available resources in an appropriate way.
2. **Investing** in innovative, basic, clinical and epidemiological research, as well as training, by rationalizing and increasing the available resources.
3. **Directing** research towards studies whose goal is the modification of the disease's natural history and the improvement of the quality of life of people with diabetes.
4. **Investing** in the implementation and search of methodologies and means of communication able to permit the effective conveyance of exact information about scientific innovation, prevention, and integrated diabetes management, as well as the promotion of the correct social representation of people with diabetes.

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PART EIGHT

RESPONSIBLE ASSOCIATIONS

In the past, non-profit, volunteer diabetes associations, in Italy, contributed to the attainment of very significant results, such as the Saint Vincent Declaration and the approval of Popular Initiative Law n. 115/87.

The achievement of legislative and regulatory goals, at a national and local level, appears to be a distinctive condition in the action of the associations involved in diabetes advocacy.

Likewise, the role played by these associations – in connecting the healthcare system, people with diabetes, their families and the larger society – also appears to be irreplaceable.

Therefore, the following is necessary:

1. **Considering** the associations to be an important resource and component of the strategies aimed at protecting people with diabetes.
2. **Facilitating** cooperation among volunteer associations of people with diabetes and their families, civic organizations, and the representatives of the scientific community.
3. **Providing** certified training and specific accreditation to the volunteer associations of people with diabetes and their families, as well as the civic organizations.
4. **Facilitating** the participation of immigrants with diabetes in the associations.
5. **Considering** the associations and civic organizations – through people trained for this purpose – to be an active party in the information and training paths concerning the rights and social protection of people with diabetes.
6. **Making** use of the cooperation of volunteer associations of people with diabetes and their families, as well as civic organizations, in the initiatives aimed at preventing diabetes.
7. **Supporting** the action of volunteers through legislative and regulatory instruments.
8. **Defining** a self-regulatory code of conduct and shared characteristics to create a reference model for the associations.
9. **Emphasizing** the activity carried out by the associations – during the conversations between healthcare professionals and people with diabetes and their family members – and promoting active participation in voluntary work.

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Diabetes Attitudes Wishes & Needs

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Associazione
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PART NINE

DIABETES AND PREGNANCY

The planning and management of pregnancy shall be protected through specific actions in terms of therapeutic education and healthcare, so as to guarantee to pregnant women and foetuses an optimum clinical condition during gestation and childbirth.

Therefore, the following is necessary:

1. **Educating** women with diabetes on the importance of planning their pregnancy, so that conception occurs under optimum conditions for embryo formation and foetal development.
2. **Favouring** check-ups to diagnose gestational diabetes and follow-ups after childbirth.
3. **Guaranteeing** that the assistance and monitoring of pregnant women with diabetes and women who develop gestational diabetes is carried out by a multidisciplinary team comprised of a diabetes specialist, a gynaecologist, an obstetrician, a nurse and a paediatrician.
4. **Receiving** pregnant women in hospital facilities adequately equipped to manage pregnancy at risk and where diabetes care is provided throughout the period of hospitalization.

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PART TEN

DIABETES IN THE DEVELOPMENTAL AGE

All children and adolescents with diabetes have the right to receive – within the paediatric sector – the best possible healthcare services, without distinction on the basis of their gender, ethnic group, religion and social conditions.

It is everybody's duty to take care of children and adolescents with diabetes by paying special attention to delicate moments in their life, i.e., when children start going to school, or during the transition to adulthood. Such moments should be facilitated through specific interventions.

Therefore, the following is necessary:

1. **Guaranteeing** to children and adolescents a school, sport and social life identical to the life of their peers without diabetes.
2. **Supporting** family members in their management of children and adolescents with diabetes.
3. **Promoting** the knowledge of symptoms in order to ensure the early diagnosis of type 1 diabetes, and thus prevent serious conditions at the onset and the subsequent complications.
4. **Ensuring** the best possible diagnostic procedures in order to precisely identify the type of diabetes and the care strategies suitable for different clinical conditions.
5. **Ensuring** access to the most appropriate, most innovative and least invasive treatment solutions.
6. **Adopting** while in conversation, an understandable language register which corresponds to the age and culture of the children and their family members.
7. **Ensuring** that the hospital and outpatient environments are sufficiently comfortable and suitable to receive children and adolescents, and that they include the presence of dedicated multi-disciplinary teams specialize in the care of child and adolescent diabetes, and are able to provide assistance to family members.
8. **Ensuring** that a child and his/her family members are always taken care of by the same multi-disciplinary team at the diabetes centre.
9. **Ensuring** that the healthcare personnel is permanently updated, in order to consistently improve their scientific, technical and communicative skills.
10. **Encouraging** physical activity, including sports, under the best possible conditions and without limitation.
11. **Promoting** the inclusion, within the basic levels of care, of school camps for the young. These should be aimed at facilitating the assumption of responsibility and self-management of diabetes.
12. **Promoting** a "network action" in the community, connecting regional paediatric diabetes centres, local centres and freely chosen paediatricians.
13. **Facilitating** the transition of adolescents from paediatric to adult diabetes specialists, in order to ensure continuity of care, by implementing a gradual process and sharing the care goals and choices.

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of the Right to Health



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PART ELEVEN

IMMIGRATION AND DIABETES

People with diabetes shall not be discriminated against on account of their language, ethnic group, country of origin, religion or status.

Therefore, the following is necessary:

1. **Facilitating** the access of immigrants to the healthcare system across the country by means of linguistic mediation services.
2. **Adapting**, whenever possible, the care plans of people with diabetes to the customs dictated by their cultural and religious traditions, as long as these do not violate human rights.
3. **Offering** permanent education courses held by multi-disciplinary teams with the support of staff – from volunteer associations of people with diabetes and their families – able to perform multilingual communication in the community and workplace.

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