INTERNATIONAL

CHARTER OF RIGHTS

AND RESPONSIBILITIES

OF PEOPLE WITH DIABETES



## INTRODUCTION

Diabetes is an urgent global public health challenge. The International Diabetes Federation estimates that diabetes now affects over 300 million people and if nothing is done, this will rise to 500 million within a generation. A similar number again is at high risk of developing diabetes.

The major burden of this epidemic is increasingly falling on low and middle-income countries and impacting disproportionately on poorer, disadvantaged and vulnerable groups, including indigenous peoples and minority communities in richer countries.

As well as the human impact, the cost to health services is great. Current estimates suggest that global healthcare spending on diabetes was USD 378 billion in 2010, equivalent to 12% of all global healthcare expenditure. This is predicted to rise to USD 490 billion by 2030.

The landmark UN Resolution 61/225 on diabetes states: "Diabetes is a chronic, debilitating and costly disease associated with severe complications, which pose severe risks for families, Member States and the entire world, and serious challenges to the achievement of internationally agreed development goals including the Millennium Development Goals".

This Charter of Rights and Responsibilities acknowledges that people with diabetes can play an essential part in confronting this silent killer if they have the rights and opportunities to act as equal partners with health care providers and Governments. It emphasises that they share the same human and social rights as people who do not have diabetes. It supports the fundamental right of people with diabetes to live a full life with fair opportunities to learn and work but it recognises also that people with diabetes have responsibilities.

# **VISION**

#### The vision of the Charter is to:

- optimise the health and quality of life of people with diabetes
- enable people with diabetes to have as normal a life as possible
- reduce or eliminate the barriers to people with diabetes realising their full potential as members of society.

# THE CHARTER

- sets out the rights as well as the responsibilities of people with diabetes
- acknowledges the wide global variety in the quality of healthcare as well as customs and practice that impact in different ways on people with diabetes
- represents the 'gold standard' in care, treatment, prevention and education to which all countries and people can aspire.



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### 1. THE RIGHT TO CARE

### People with diabetes have the right to:

- early diagnosis and affordable and equitable access to care and treatment, regardless of race, ethnicity, gender and age, including access to psychosocial care and support
- receive regular, reliable advice, education and treatment in accordance with evidence-based practice that centres on their needs, irrespective of the setting in which they receive that care
- benefit from proactive health sector community outreach, education and prevention campaigns in every healthcare setting
- access to high-quality services and care during and after pregnancy and childbirth
- access to high-quality services and care during childhood and adolescence, recognising the special needs of those not necessarily in a position to represent themselves
- appropriate transitional care, addressing the progression of the disease and the changes that occur with age
- continuity of appropriate care in disaster and emergency situations
- be treated with dignity and respect including respect for individual, religious or cultural beliefs and parental insights - by healthcare providers, and feel free to make complaints about any aspects of diabetes services without detriment to their care and treatment
- information relating to their diabetes being kept confidential and not disclosed to third parties without their consent and the choice whether or not to take part in research programmes, without detriment to care and treatment
- advocate, individually and collectively, to health providers and decision makers for improvements in diabetes care and services.



## 2. THE RIGHT TO INFORMATION AND EDUCATION

# People with diabetes and the parents or carers of people with diabetes have the right to:

- information and education about diabetes, including how it can be prevented, how early detection in high risk individuals is an advantage, how the disease can be managed effectively and how to access education and clinical resources
- high quality diabetes self-management education at diagnosis and whenever needed that integrates the clinical, behavioural and psychosocial aspects of diabetes in a group or individually
- be involved in assessing, planning and implementing as well as monitoring their own care and health goals
- reliable information about the names and dosage of any therapies and medication, their actions and potential side-effects and interactions with other medical conditions and therapies, specific to the individual
- individual access to their medical records and other relevant information if requested and the right for that information to be shared.



# 3. THE RIGHT TO SOCIAL JUSTICE

## People with diabetes have the right to:

- be a fully engaged member of society, treated with respect and dignity by all, without feeling the need to conceal the fact they have diabetes
- affordable medicines and monitoring technologies
- be treated fairly in employment and career progression while acknowledging that there are certain occupations where identifiable risks may limit the employment of people with diabetes
- be treated with respect and dignity by all sections of society
- not to be discriminated against in the provision of all forms of insurance cover and in applying for a driving licence
- be fully supported in pre-school activities, schools, during extra-curricular
  activities and social clubs as well as in workplaces and be given time
  to attend medical appointments as well as the time and privacy to selftest and administer medicines in a clean and safe environment
- create or participate in a representative patient organisation and seek the support for that organisation from health and health-related bodies and civil society.

## 4. RESPONSIBILITIES

### People with diabetes have the responsibility to:

- share information with their healthcare providers on their current state
  of health, all types of medicines they are using, allergies, social setting,
  lifestyle behaviour and any other information that would be relevant
  in a health provider determining the most suitable treatment and advice
- manage their agreed care and treatment plan
- adopt, implement and monitor healthy lifestyle behaviours as part of their self-management of diabetes
- share with their healthcare providers any problems they experience with their recommended treatment plan, including any barriers to its successful implementation
- inform family, school, work and social colleagues they have diabetes so that they can be supportive to people with diabetes, if and when needed
- show consideration and respect for the rights of other people with diabetes and their healthcare providers.

This Charter embraces the principles of health and human rights of the Universal Declaration of Human Rights, and builds on major human rights instruments such as the Convention on the Rights of the Child (CRC), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and the Convention on the Rights of People with Disabilities.

We urge all patient and professional organisations and nation states to work to embed these principles in national plans for diabetes care, prevention, research and education and to ensure their implementation is regularly monitored and reviewed.



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