



THE PATIENTS' CHARTER FOR TUBERCULOSIS CARE (Edition 2010)

The Patients' Charter (PCTC) outlines the rights and responsibilities of people with tuberculosis. It empowers people with the disease and their communities through this knowledge. Initiated and developed by TB patients from around the world, the Charter makes the relationship with health care providers a mutually beneficial one.

The Charter sets out the ways in which patients, the community, health providers, both private and public, and governments can work as partners in a positive and open relationship with a view to improving tuberculosis care and enhancing the effectiveness of the health care process. It allows for all parties to be held more accountable to each other, fostering mutual interaction and a 'positive partnership'. Developed in tandem with the International Standards for Tuberculosis Care(1) to promote a 'patient-centered' approach, the Charter bears in mind the principles on health and human rights of the United Nations, UNESCO, WHO, Council of Europe, as well as other local and national charters and conventions(2).

The Patients' Charter practices the principle of Greater Involvement of People with TB or GIPT(3). This affirms that the empowerment of people with the disease is the catalyst for effective collaboration with health providers and authorities, and is essential to victory in the fight to stop TB. Accordingly, the PCTC is included as a key element of the WHO STOP TB Strategy, and was launched by Dr. Lee, DG of WHO on World TB Day 2006. The Patients' Charter, the first global 'patient-powered' standard for care, is a cooperative tool, forged from common cause, for the entire TB Community.

PATIENTS' RIGHTS

Care

- The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture or having another illness.
- The right to receive medical advice and treatment which fully meets the new International Standards for Tuberculosis Care, centering on patient needs, including those with X/MDR-TB or TB-HIV co-infections, and preventative treatment for young children and others considered to be at high risk.
- The right to benefit from proactive health sector community outreach, education and prevention campaigns as part of comprehensive care programs.

Dignity

- The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice or discrimination by health providers and authorities.
- The right to quality health care in a dignified environment, with social support from family, community and national programs.

Information

- The right to information about what health care services are available for tuberculosis, and what responsibilities, engagements, and direct or indirect costs, are involved.
- The right to receive a timely, concise and clear description of the medical condition, with diagnosis, prognosis (an opinion of the likely future course of the illness), and treatment proposed, with communication of common risks and appropriate alternatives.
- The right to know the names and dosages of any medication or intervention to be prescribed, its normal actions and potential side-effects, and its possible impact on other conditions or treatments.
- The right of access to the medical record concerning the patient's condition and treatment, and a copy if requested by the patient or a person authorized by the patient.
- The right to meet, share experiences with peers and other patients, and to voluntary counseling at any time from diagnosis through treatment completion.

Choice

- The right to a second medical opinion, with access to previous medical records.
- The right to refuse surgical interventions if chemotherapy is at all possible, and to be informed of the likely medical and statutory consequences.
- The right to choose whether or not to take part in medical research programs without compromising the quality of care.

Confidence

- The right to have personal privacy, dignity, religious beliefs and culture respected.
- The right to have information relating to the medical condition kept confidential, and released to other authorities contingent upon the patient's consent.
- The right to health care services in facilities that practice effective infection control.

Justice

- The right to make a complaint through channels provided for this purpose by the health authority, and to have any complaint dealt with promptly and fairly.
- The right to appeal to a higher authority if the above is not respected, and to be informed in writing of the outcome.
- The right to vote in open elections for patient representatives on health related bodies, and to develop accountable systems of representation to defend the rights of patients.

Organization

- The right to join, or to establish, organizations of people with or affected by TB, and to seek support for the development of these clubs, peer support groups, and community based associations through the health providers, authorities, and civil society partners.
- The right to participate as 'stakeholders' in the development, implementation, monitoring and evaluation of policies and programs for TB Care with local, national and international health authorities.

Security

- The right to job security after diagnosis and /or appropriate rehabilitation upon 'cure'.
- The right to nutritional security or food supplements that are necessary to meet treatment regime requirements.
- The right to anti-tuberculosis drugs and diagnostics that are Quality Assured by a stringent authority or WHO pre-qualification.

PATIENTS' RESPONSIBILITIES

Share Information

- The responsibility to provide the health care giver as much information as possible about present health, past illnesses, any allergies and any other relevant details.
- The responsibility to provide information to the health provider about contacts with immediate family, friends and others who may be vulnerable to tuberculosis or may have been infected by contact.
- The responsibility to inform family and friends, and to share lessons learned of TB.

Follow Treatment

- The responsibility to follow the prescribed and agreed treatment plan, and to conscientiously comply with the instructions given to protect the patient's and other's health
- The responsibility to inform the health provider of any difficulties or problems with adhering to treatment, or if any part of the treatment is not clearly understood.

Contribute to Community Health

- The responsibility to contribute to community well being by encouraging others to seek medical advice if they exhibit the symptoms of tuberculosis.
- The responsibility to show consideration for the rights of other patients and health care providers, understanding that this is the dignified basis and respectful foundation of the TB Community.
- The responsibility to help family, friends and neighbors adhere to treatment, from start to completion with cure.

Show Solidarity

- The moral responsibility of showing solidarity with other patients, marching together towards cure.
- The moral responsibility to share knowledge gained during treatment, and to pass this expertise to others in the community, making empowerment contagious.
- The moral responsibility to join in efforts to make the community TB Free.

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1. International Standards for Tuberculosis Care:
<http://www.who.int/tb/publications/2006/istc/en/index.html>
 2. United Nations CESCR General Comment 14 on the right to health:
[http://www.unhcr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En](http://www.unhcr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En)
- WHO Ottawa Charter on health promotion:
www.who.int/healthpromotion/conferences/previous/ottawa/en
- The Council of Europe Convention for the Protection of Human Rights and Dignity/
biology and medicine:
<http://conventions.coe.int/treaty/EN/Treaties/Html/164.htm>
- UNESCO Universal Draft Declaration on Bioethics and Human Rights:
http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html
 3. Greater Involvement of People with Tuberculosis (GIPT):
<http://www.worldcarecouncil.org/content/greater-involvement-people-tb-gipt>

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Help turn these words into practice, and your rights into realities. Join the mobilization in your country for the implementation of the Patients' Charter for Tuberculosis Care. In common cause, with mutual respect, together we can raise the standards of care for people with TB and TB-HIV co-infection.

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Learn more / downloads at <http://www.patientscharter.org>

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TBCTA
The Tuberculosis Coalition for Technical Assistance