

The Patients' Charter for Tuberculosis Care

The Patients' Charter 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 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 for Tuberculosis Care practices the principle of Greater Involvement of People with TB. 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. 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

1. Care

- a. 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.
- b. 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 MDR-TB or TB-HIV coinfections, and preventative treatment for young children and others considered to be at high risk.
- c. The right to benefit from proactive health sector community outreach, education and prevention campaigns as part of comprehensive care programs.

2. Dignity

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

3. Information

- a. The right to information about what health care services are available for tuberculosis, and what responsibilities, engagements, and direct or indirect costs, are involved.
- b. The right to receive a timely, concise and clear description of the medical condition, with diagnosis, prognosis (an opinion as to the likely future course of the illness), and treatment proposed, with communication of common risks and appropriate alternatives.
- c. 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.
- d. The right of access to medical information which relates to the patient's condition and treatment, and a copy of the medical record if requested by the patient or a person authorized by the patient.
- e. The right to meet, share experiences with peers and other patients, and to voluntary counseling at any time from diagnosis through treatment completion.

4. Choice

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

5. Confidence

- a. The right to have personal privacy, dignity, religious beliefs and culture respected.
- b. The right to have information relating to the medical condition kept confidential, and released to other authorities contingent upon the patient's consent.

6. Justice

- a. 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.
- b. The right to appeal to a higher authority if the above is not respected, and to be informed in writing of the outcome.

7. Organization

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

8. Security

- a. The right to job security after diagnosis or appropriate rehabilitation upon completion of treatment.
- b. The right to nutritional security or food supplements if needed to meet treatment requirements.

PATIENTS' RESPONSIBILITIES

1. Share Information

- a. 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.
- b. 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.

2. Follow Treatment

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

3. Contribute to Community Health

- a. The responsibility to contribute to community well being by encouraging others to seek medical advice if they exhibit the symptoms of tuberculosis.
- b. 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.

4. Solidarity

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

Help turn these words into realities. Support the drive towards implementation in the community. Sign-Online at <http://www.wcc-tb.org> or Sign-Up by SMS text: +33 679 486 024. In common cause, with mutual respect, together we can raise the standards of care.

1. International Standards for Tuberculosis Care: <http://www.worldcarecouncil.org/pdf/>

2. United Nations CESCR General Comment 14 on the right to health:

<http://www.worldcarecouncil.org/pdf/>

- WHO Ottawa Charter on health promotion: <http://www.worldcarecouncil.org/pdf/>

- The Council of Europe Convention for the Protection of Human Rights and Dignity/ biology and medicine: <http://www.worldcarecouncil.org/pdf/> - UNESCO Universal Draft Declaration on Bioethics and Human Rights: <http://www.worldcarecouncil.org/pdf/>

Comments warmly welcome: voices@wcc-tb.org

version pdf: <http://www.worldcarecouncil.org/pdf/>

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