

## **Patients' Charter of the Tuberculosis Community**

**The aim of the Patients' Charter of the Tuberculosis Community is to outline both the Rights and Responsibilities of those infected by TB, and to empower people with the disease and their communities through this knowledge.**

Knowing and understanding these rights and responsibilities will make the relationship with health care providers a mutually beneficial one. The Charter sets out the ways in which patients, the community and the health providers, both private and public, 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. The empowerment of patients is essential to victory in the fight to stop TB.

The Charter, developed in tandem with the **International Standards of Tuberculosis Care**(1) to promote a 'patient-centered' approach, bears in mind the principles of the United Nations CESCRC General Comment 14 on the right to health(2), the WHO Ottawa Charter on health promotion(3), and the Council of Europe Convention for the Protection of Human Rights and Dignity with regard to the application of biology and medicine(4), as well as other local and national charters and conventions. Upholding these basic principles, rights and responsibilities allows for all parties to be held more accountable to each other, fostering a mutual interaction between patients, their families and communities, health providers and governments. The Patients' Charter is a cooperative tool, forged from common cause, for the TB Community.

### **PATIENTS' RIGHTS**

#### **1. To 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 of 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.

#### **2. To 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. To Information**

- a. The right to information about what health care services are available for tuberculosis, and what engagements, direct or indirect, 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 if requested.
- 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. To Choose**

- a. The right to accept or refuse any medication, investigation or treatment, and to be informed of the likely medical and statutory consequences within the context of a communicable disease (5).
- b. The right to a second medical opinion, with access to previous medical records.
- c. The right to choose whether or not to take part in research programs without compromising care.

## **5. To Privacy**

- a. The right to have personal privacy, dignity and religious and cultural beliefs 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. To Complain**

- 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. To Organize**

- a. The right to join, or to establish, organizations of people living 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 and evaluation of TB prevention and control policies and programs in local, national and international health authorities (6).

## **8. To Security**

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

## **PATIENTS' RESPONSIBILITIES**

### **1. To 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. To 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 (5).
- 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. To defend the community**

- a. The responsibility to defend the community 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 of the TB community.

### **4. To be empowered**

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

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1. Read the draft International Standards for Tuberculosis Care:

<http://www.tbvtv.org/pdf/InternationalStandardsofTBCare.pdf>

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

<http://www.tbvtv.org/pdf/GeneralCommentNo.14.pdf>

3. WHO Ottawa Charter on health promotion:

[http://www.tbvtv.org/pdf/ottawa\\_charter\\_hp.pdf](http://www.tbvtv.org/pdf/ottawa_charter_hp.pdf)

4. The Council of Europe Convention for the Protection of Human Rights and Dignity/ biology and medicine:

[http://www.tbvtv.org/pdf/CoE\\_HRBioMed.pdf](http://www.tbvtv.org/pdf/CoE_HRBioMed.pdf)

5. Input concerning MDR specific issues (isolation, toxicity of treatment, etc) are welcome for the next draft.

6. The GIPT (Greater Involvement of People with Tuberculosis) Principles and Practices are currently being drafted. Input and ideas welcomed, send to [voices@tbvtv.org](mailto:voices@tbvtv.org)

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Comments welcome : send to Case Gordon ([gordon@tbvtv.org](mailto:gordon@tbvtv.org)) - next draft out 12.12.05

version pdf: <http://www.tbvtv.org/pdf/patientscharterdraft2.pdf>

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