



# Tuberculosis Survival Project Summer 2008 Newsletter

## All change – TBSP Taken Over by New Charity

The Tuberculosis Survival Project (TBSP) has been through some changes. For just over two years the financial administration of the TBSP was being temporarily being handled by our sister organization,



TB Alert. The project has now been adopted by a new charity called the Advocacy Partnership. Here at TBSP we would like to express our gratitude and thanks to all at TB Alert who have supported TBSP over the past couple of years. Their assistance and enthusiasm has helped the website to grow and develop to be a useful tool for people with TB/MDR-TB, or those that want to find out more about the disease. The TBSP website gets around 500 hits a month from people looking for help, support and information.

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## TBSP in the News

TBSP featured in a local BBC news programme called South East Today.

It was after thousands of letters were sent out to patients after they may after they may have been exposed to a health care worker with TB.

To see the feature go to:

[http://news.bbc.co.uk/player/nol/newsid\\_7240000/newsid\\_7243300/7243353.stm?bw=nb&mp=wm&news=1&nol\\_storyid=7243353&bbcws=1](http://news.bbc.co.uk/player/nol/newsid_7240000/newsid_7243300/7243353.stm?bw=nb&mp=wm&news=1&nol_storyid=7243353&bbcws=1)

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## Patient Focus: Rest and Sleeping



Getting enough rest and sleep is important to everyone. It is the time when the human body regenerates and repairs itself. For anyone who has been sick getting enough rest and sleep is vital and the same is true especially so for people who have tuberculosis. Like diet and exercise, rest and sleep was one of the pillars of TB treatment before the advent of anti-TB medication. Indeed, most doctors 100 years ago absolutely insisted on complete bed rest as a vital tool in the treatment of TB.

In one book of the time called *The Tuberculosis Handbook* by A.H.G Burton it says: "Patients who are feverish on admission must be treated for this

*symptom by rest. If the fever is slight, not over 99 degrees F., simple rest in bed may be sufficient, visits not being allowed if they excite the patient, and no business or other matters tending to excite him should be permitted. If the fever is high, over 101 degrees F., absolute rest may be ordered by the doctor. He will not feed or attend to himself in any way. The nurse must wash him, carefully, a little at a time without disturbing him."*

Times have changed since this kind of advice was given. For a start all patients with TB, whether they are ill at home or hospital should be encouraged to do as much as they can for themselves. Washing when they get up and if they feel well enough getting dressed. Although the reliance on complete bed rest for people with TB doesn't feature like it used to in today's TB treatment regimens, rest and sleep are still important to get better.

If you feel the need to rest or sleep, then you simply should. Some people feel bad about doing this, especially if it is during the day and they were leading very busy lives before they become ill. They can feel as if they are being lazy and try and do more that they are really physically capable of. This is not beneficial to getting well. You should be kind to yourself. Rest when you need to. It can be in a chair, or you may want to lay down on your bed. If you fall asleep then that is good too. You can make things more comfortable for yourself in your bedroom by having the things you need close to hand. If you have trouble sleeping during the daytime then some good curtains that keep the light out at the window may be a good idea. Getting enough rest and sleep is integral to recovering from TB. Doing too much before you are ready may only serve to set you back. The key is to take things more slowly if you are unwell.

It is true that some people do not understand the nature of TB, or even possibly what it is like to be so ill that you don't have the energy to do anything. You mustn't feel pressured by such people. Do not be afraid to rest, even if you have other commitments. There is nothing wrong with saying; "No, I can't do that right now" and putting your head down. It isn't lazy, it is doing what you have to do to get better.

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## Do you want to share your experience of having TB/MDR-TB with others?

The Tuberculosis Survival Project would like to hear from you. If you would like to share your experience with others then why not write about your own TB story. Take a look at the READ STORIES section of the project website [www.tbsurvivalproject.org](http://www.tbsurvivalproject.org) if you need to get an idea of what other people have done. Stories need to be no more than 1000 words long and you must give permission for your story to be included on the website.

### Recently diagnosed with TB/MDR-TB?

Did you know that TBSP can offer you one-to-one support? We can't give out medical advice as we are not qualified to do so, but if you have a question that we are unable to answer, we can find someone who can!

Sometimes it is difficult to know where to turn, some people also find it hard to speak to health care workers about how they are feeling. Having TB can feel very isolating and lonely. There is no need to be

We at TBSP can be a listening ear if you are having problems understanding or getting used to your TB diagnosis. We know because we have had TB too. To find out more see the TBSP website at <http://www.tbsurvivalproject.org/mentoring.html>.

### **Did somebody say something....?**

**“I took out my hand mirror and prepared to do something with my hair, but one look at my dry grey face and the sphagnum moss hair made me want to bang my head against the back of the bed and scream. I took out my lipstick and Sylvia said immediately “No, no, Betty, patients are not allowed to wear make-up except on visiting day.” This made me want to bang her head against the back of the bed and scream. To make matters worse my blood was all crouched shivering in the vicinity of my heart instead of coursing warmly down to my icy extremities. I slammed the drawer of my stand shut and lay back and hated morning.**

**Betty Macdonald – The Plague and I**

### **Do you have something to say?**

If you have a story or something else that you want to share with others, then drop us a line via the project website. Alternatively you can email [paulthornlondon@hotmail.com](mailto:paulthornlondon@hotmail.com).

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