

the tuberculosis survival project ...your cure, your life

TB TIPS

→ **ADVICE FOR PEOPLE WITH
TUBERCULOSIS**
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Stop TB Partnership

WELCOME:

YOUR INFORMATION

- TB is a curable illness when you take your TB medication like the doctor or nurse tells you to.
- It is very important that you don't stop taking your TB medication, until the doctor or nurse tells you to.
- If you are having problems or are unsure about any aspect of your TB medication, speak to the doctor or nurse/s who are caring for you. Use this page to be sure you have their contact details. They are there to help and want you to get better. ●

→ Your TB Nurse is:

→ Your Hospital Doctor is:

→ The Clinic Address is:

→ Contact Number:

→ Email:

INTRODUCTION

- ➔ If you have been diagnosed with tuberculosis (TB) – “standard” or multidrug-resistant (MDR) – this booklet is for you. It contains tips – practical advice, suggestions, guidance and information – to help you cope with your illness. The tips are based on common sense and the personal experience of other TB patients – people who know what it is like to be diagnosed, to be isolated in hospital and to receive TB or MDR-TB treatment. Some tips cover aspects that may not be obvious to the doctors or nurses caring for you; some may apply to your situation and some may not. Take those that you find useful and leave the others. We hope that this booklet will help you on your personal journey through the treatment and we wish you a speedy recovery.
- ➔ If you would like to share any tips or comments on your experience with TB or MDR-TB, please send them to us for possible inclusion in a future edition of this booklet. Either send an email to our editor at www.tbssurvivalproject.org or write to:

The Tuberculosis Survival Project, c/o TB Alert,
Community Base, 113 Queens Road,
Brighton, BN1 3XG, United Kingdom.

- ➔ The original version of *TB Tips: Advice for People with Tuberculosis* appeared in the first edition of *The Tuberculosis Survival Handbook*, the highly acclaimed handbook on TB and MDR-TB by Paul (Mayho) Thorn, published in 1999. A second edition, published by Merit Publishing International in 2006, is available from www.amazon.co.uk.

- ➔ This booklet, *TB Tips: Advice for People with Tuberculosis*, is brought to you by The Tuberculosis Survival Project, a member of the Lilly MDR-TB Partnership. ●

TB TIPS:

DIAGNOSING TB/MDR-TB

- TB is a disease caused by a bacteria that is transmitted by tiny airborne droplets when someone who has TB coughs – or maybe laughs, sings or talks. If anyone else breathes in the TB germ there is a chance that they may get infected with TB and go on to develop the active TB disease.
- TB can occur in any part of the body, but it occurs most commonly in the lungs. Usually, the symptoms are a cough, possibly bloodstained phlegm (sputum), fever, night sweats, loss of weight, loss of appetite and a general feeling of being unwell.
- MDR-TB is TB that has become resistant to some of the drugs that are usually used to treat the disease. Having either TB or MDR-TB is very serious and, if left untreated, both can kill. The good news is that TB and MDR-TB are curable if they are diagnosed and appropriate treatment is given.
- If you have any of the symptoms mentioned above, or think you may have TB, then you need to find out

for sure if you have it or not.

- ➔ TB is curable. If you have been exposed to TB by someone who has it, do not panic.
- ➔ If you are in contact with someone who has TB, tell your doctor so that he or she can carry out appropriate tests to see if you need treatment.
- ➔ Depending on your personal circumstances, your doctor may consider it appropriate to put you on medication to prevent you from developing TB.
- ➔ If you develop any of the symptoms of TB – a persistent cough, blood-stained phlegm (sputum), fever, night sweats, loss of weight, loss of appetite or if you feel generally unwell – get a check-up from your doctor. Do not leave anything to chance – the sooner TB is diagnosed and treated, the sooner it will be cured. (The symptoms listed above vary from person to person. However, the presence of these symptoms – either alone or in any combination – should be checked by a doctor.)
- ➔ You may sometimes have to wait a long time for test results. Try to be patient. It serves no purpose to torture yourself during this time.

- ➔ While you wait for your test results you might have to spend some time apart from people who are considered vulnerable. It can be hard to be separated from family and friends during a time such as this but it is a necessary precaution. It is better to be safe!
- ➔ If you do not understand what a doctor is telling you, ask for clarification – and, if you still do not understand, ask again and again until you do. Take a notepad if necessary. Do not feel intimidated – doctors are human beings too! They have an extensive knowledge of the disease and, unless you specifically ask what you would like to know, they may assume that you understand more than you actually do.
- ➔ Invite a trusted friend or family member to accompany you when you go to see the doctor. It helps to be able to talk it over afterwards with someone you know well. It also helps your family and friends to know and understand what is happening to you.
- ➔ A “latent” infection occurs when someone breathes in the TB germ at some point in their life and becomes infected but does not develop the disease. If you are found to be “latently” infected with TB, you

are not infective and therefore not dangerous to others. Of the people who get infected, only about 10% develop the “active” TB disease. However, if the body’s defence system gets weakened in any way – for example, if a person becomes HIV-positive – they may then be at more risk of developing “active” TB. Talk to your doctor about this.

- ➔ If the TB doctor or nurse needs to find out who you got TB from or if you have passed it on to anyone else, they may decide to initiate a procedure called “contact tracing”. This means that they will ask you many questions about where you have been and who you have been in contact with. You may feel embarrassed or awkward about disclosing names of people – but again, it is best to be safe. One of the people you name could even be the person who happened to infect you; that person may also be in need of help and treatment.
- ➔ Nurses will be happy to talk to you if you need help. It is part of their job and it can be easier to communicate with a nurse than with a doctor; they are often more approachable. ●

TB TIPS:

TREATING TB

- ➔ Both TB and MDR-TB are curable if you take all the TB medicine given to you and do not miss any doses. It is important to stop taking TB medicine only when a TB doctor or nurse tells you to do so. This is because if you do not take all the TB medicine, or if you stop taking it too early, there is a chance that the TB could come back; it would be more difficult to treat a second time around.
- ➔ Taking TB medicine is not always easy so it is best to be organized and disciplined about it. If you have trouble taking it, you should always tell your TB doctor or nurse. They should be able to suggest ways to help, or directly assist you to take your TB or MDR-TB medicine. ●

STORING YOUR TB MEDICINE

- ➔ **REMEMBER:** Always keep all medication safely out of reach of children.
- ➔ There are ways to store your TB medicines other

than simply leaving them in their original bottles in a plastic bag. For example, you can store a day's supply of medicine in a container such as a Dosett™ or Medimax™ box or even a phlegm (sputum) sample container. Keeping a day's supply in a separate container helps you keep track of what you have taken and what you still have to take that day. However, you should be aware of this warning: some drugs must be stored separately; if not, they lose their potency. If you decide to keep your medicines in a container other than the one supplied by the pharmacist, you must:

- ➔ First, check with the pharmacist, doctor or nurse if it is acceptable to use an alternate container; show them the container you plan to use; and
- ➔ Second, **ONLY** store one day's supply in a separate container at any time.
- ➔ If you use the phlegm (sputum) sample containers, label one (or two) for each day of the week and indicate if it is the morning or evening dose (AM or PM). You can easily carry these containers around with you in a handbag or pocket. If you don't want the tablets to rattle, add some cotton wool before you put the lid on. ●

TAKING YOUR MEDICATION

- ➔ Some people with TB or MDR-TB may be fortunate enough to have access to a system called Direct Observed Therapy (DOTS). This is globally recognized as the best system for treating TB or MDR-TB. Essentially, it means that a TB nurse or some other trusted person watches you take your daily TB tablets and keeps a record of it. Many people find the idea intrusive but, if you ask anyone who has received TB treatment with DOTS, they will invariably say how useful it has been to have a qualified “friend” help them on a regular basis through their treatment. People who are on DOTS have a much higher percentage chance of being cured of TB or MDR-TB than those who are not. If you are not on DOTS, ask your TB doctor or nurse if they operate a similar system that would be suitable for you.
- ➔ Treating TB means taking a lot of tablets for a long time (six to nine months – possibly longer for MDR-TB). If you feel as if your body is not going to cope with all the tablets or if you find it physically difficult to take such a large quantity:
- ➔ Try to set aside time to take them;

- ➔ Try to take them with yoghurt or a glass of water to help them go down – this may also make the medicine act more gently in the stomach.
- ➔ If you swallow all the tablets at once you may feel sick or even vomit. If you have a problem with sickness, tell your TB doctor or nurse – they may be able to help you with this. If you actually vomit after you take the tablets you won't absorb the medicine and the illness may not be cured.
- ➔ If it is difficult for you to remember to take your TB medicine, try putting it in a prominent place to help you remember – for example, by your tea or coffee in the morning. You can also try using an alarm, a bleeping watch or a computer as a reminder. Alternatively, ask a reliable friend or a family member to remind you to take it.
- ➔ The most important thing with your TB medication is to plan ahead. Know when your prescription is due to run out and how to get more tablets. Always carry an extra dose with you. If you are travelling, never pack all your medicines in a suitcase that will be put into a baggage hold. Baggage can get delayed, lost or stolen en route so always carry extra doses with you.

- ➔ Constantly affirm to yourself that the TB medicine is doing you good. Remind yourself that, if you keep taking it regularly, the day will come when you won't need to take any more. Eventually you will be cured and you will be very glad that you had the self-discipline to persevere.
- ➔ If you regularly smoke or drink alcohol, speak to your doctor about it. Smoking damages your health and it is unlikely that alcohol will be compatible with the TB medication. You may be able to get extra help if you are a smoker or a heavy drinker.
- ➔ You may have thought about trying an alternative therapy such as a traditional treatment, a homeopathic remedy or even prayer rather than the TB medicine. We strongly advise you not to do this. An alternative therapy on its own will not cure TB or MDR-TB but it can be a useful addition to conventional TB treatment. ●

MEDICATION FOR CHILDREN

- ➔ Giving TB medicine to children can pose special problems. If you are a parent, try not to get upset if your child refuses to take the tablets or has problems swallowing them – the situation will only

get worse if it leads to a quarrel every day.

- ➔ Try to remember that taking TB medicine will eventually become a regular routine.
- ➔ If necessary you could resort to bribery by, for example, promising your child a big surprise at the end of the treatment.
- ➔ Discuss any problems, such as point-blank refusal to take the TB medicine, with your TB doctor or nurse. Some TB drugs come in syrup form and are easier to swallow. ●

COPING WITH SIDE EFFECTS

- ➔ Some of the side effects of TB medicine, particularly the treatment for MDR-TB, can be difficult to live with. Some people need additional counselling to get them through their treatment. Tell your TB doctor or nurse if you are struggling, emotionally or mentally, to take your TB medicine. They may be able to offer additional help.
- ➔ You may find that you develop thrush in your mouth and/or throat after a while. Thrush is a fungal infection that can appear when a person takes

antibiotics for a long time. It is also a common affliction in people who have a weakened immune system – anyone who is HIV-positive for example. Thrush can make your mouth feel painful and small white patches may appear in your mouth and throat. Tell your doctor if this happens.

- ➔ Doctors are very good at treating TB and MDR-TB. They may, however, not always understand how the side effects of the medicine can make you feel. If your doctor seems unsympathetic, ask to see a TB nurse. Sometimes the nurses know other ways of dealing with side effects. If neither your doctor nor the nurses are helpful or have any positive suggestions, you may decide to speak to a doctor or nurse elsewhere.

- ➔ If you are not already on DOTS (the Direct Observed Therapy system described above), ask your TB doctor or nurse if it would be appropriate for you. You will then be able to discuss any side effects and their potential solutions in more detail with the person who is helping you through your treatment. This is a highly recommended strategy! ●



TB TIPS:

MANAGING TIME IN ISOLATION

Not everyone with TB has to spend time in isolation.

- ➔ People with TB or MDR-TB do not usually have to stay in hospital. However, if a person is very sick or is having great difficulty taking the TB medicine, he or she may be admitted and perhaps isolated from the other patients by being given a room alone. This may be a side room with the door kept closed or a special isolation room – a negative-pressure isolation room – where the air pressure is controlled to ensure that no TB germs can escape from the room and infect other patients.
- ➔ If you happen to be put in isolation in hospital you may find that you have to spend a lot of time in your room. You will probably not be allowed to leave it unless the TB doctor or nurse says you can.
- ➔ You may lose an appreciation of the passage of time while you are in isolation. Every day can feel the same as the one before. This can become very confusing and you may find it difficult to decide what happened when.

- ➔ The suggestions below are to help you during your time in isolation.
- ➔ Make sure that people close to you know where you are!
- ➔ If there is no clock in the room ask the nurses if you can have one or ask a friend to bring one in. Ideally, try to get a clock that doesn't have a loud tick. Listening to a ticking clock all day can be very annoying!
- ➔ It is really important to try to establish some sort of routine; it will help you keep track of time.
- ➔ Open your blinds or curtains when you get up; close them when you go to sleep. If you sit in a darkened room you may start to confuse day and night.
- ➔ If you are well enough, get up and get dressed.
- ➔ If you have a television in your room, try to watch scheduled programmes such as the news or your favourite soap opera. These will act as regular markers to help structure your day.
- ➔ We advise that you avoid watching children's television programmes. It is not uncommon to regress

emotionally after having been in isolation for a long period of time. This can be linked to a childhood experience such as being sent to the bedroom for being naughty. Isolation can begin to feel like a similar punishment and this emotion tends to be reinforced by watching children's television. This is irrational; you are in isolation to help you get better and to prevent you passing the infection on to others.

- ➔ Most hospitals have someone who comes around selling newspapers and magazines. Make sure that you are not left out. Try to keep up with what is going on in the world outside the four walls of your room. ●

TB TIPS:

COMMUNICATION

- ➔ The ability to have communication with other people when you are in hospital is important, especially if you are alone and in isolation. The tips below are to help you establish good communication – verbal and non-verbal.
- ➔ Verbal communication is relatively simple to ensure – you will have visitors to speak to and you should also be able to arrange access to a telephone.
- ➔ The issue of non-verbal communication, however, is neither so obvious nor simple to resolve. Everyone who comes into your isolation room – visitors and carers – will probably have to wear a face-mask to reduce the risk of getting infected. You may be surprised at how much you will miss their non-verbal communication – the subtle signs and nuances conveyed by a person's facial expressions – and how severely this is limited by a mask. The warmth of a simple smile, for instance, cannot be communicated. Try these suggestions.

- ➔ Many hospitals do not allow the use of mobile phones since they can affect sensitive electronic medical equipment. If you have a phone by your bed – great! Find out, however, what costs you have to pay. Are you liable for the cost of the calls you make and is there a rental fee for the phone? Calls from a hospital phone can sometimes be very expensive so find out the rate per call. However, if you decide not to make outgoing calls, you can still receive incoming calls and that should not cost you anything. Ask your friends and family to phone you regularly.

- ➔ If there is not a telephone in your room, speak to the staff about it. It is important to be able to maintain contact with the outside world and communicate with your friends and family. The staff should understand and hopefully be able to sort this out. Remember, if you get a phone in the room, there is a chance that it will be there for the next occupant.

- ➔ If there is a problem with having your own phone, check if there is a pay phone you can use. There may be one on a trolley in the ward that can be brought to your bedside. Give the number to your friends and family but explain to them that the phone is not in your room for you to answer. Ask the nurses if they can take messages for you.

- ➔ The people who are caring for you will probably wear masks so, as mentioned above, you will not know what they look like and non-verbal communication will be severely restricted. Mention if you find this disturbing. Your carers cannot remove their masks to show you their faces but you can ask them to show you photographs of themselves. That way you can get to know what each one looks like. If one of your friends or a family member has a digital camera you could perhaps ask them to take a photo of your carers for you. It will also help to make a note of their names. ●

TB TIPS:

REGAINING CONTROL OF YOUR LIFE

- ➔ You may feel that, being ill, you have lost control over certain aspects of your life or have lost your freedom. Your liberty in hospital isolation may indeed be curtailed but you can still establish some control over your environment and circumstances so that you enjoy a sense of independence. The following tips may help you.
- ➔ **REMEMBER:** You are undergoing treatment. At times it may seem hard but a relatively short time of discomfort should ensure a complete return to health.
- ➔ If you are in an isolation room, warning signs on the outer door will tell people what to do when they come in. Add a sign of your own that says, "Please knock before you enter." A strange contradiction of isolation is that you have very little privacy. It can be very intrusive to have a hospital worker coming in to clean your room just as you are drying yourself or getting dressed after taking a shower!

- ➔ Ask a friend or a family member to bring you some of your personal effects from home – pictures or posters for example. This will help to personalize your room so it does not look so bare.
- ➔ Try rearranging the furniture in your room – this will help make it your own space and give you back a sense of control.
- ➔ Keep a diary, draw or do some other creative activity to help the time pass. It is good to feel you are achieving something.
- ➔ If your isolation room has a kettle and a refrigerator you will be able to make your own tea when you feel well enough. Not having to ask someone to bring you a cup of tea every time you want one will give you back some independence.
- ➔ If you will be staying in hospital for a while, you will need clean clothes. Ask the nurses if they can arrange to have your clothes washed. There are usually facilities for this but make sure to mark your clothes in some way – with a name tag for example – so they can be identified and returned to you.
- ➔ If you have any space in your room, you may feel like

doing a few exercises. Isolation, compounded by the loss of weight caused by TB, leads to muscle wasting. It is therefore important to try to maintain some muscle tone. Ask if you can see a physiotherapist. He/she may be able to offer some equipment and/or advice. You may even be fortunate enough to have access to an exercise bicycle. Some people manage to establish an exercise regime while they are in isolation but you must remember not to push things too hard. Be realistic about what you can do physically.

- ➔ Ask to see a psychologist on a regular basis if you are having trouble with the combination of being in isolation and the side effects of the medication. Frustration, resentment and loss of control are common feelings at this time and a psychologist can help you deal with them.
- ➔ It is important for your self esteem to make an effort with your personal appearance. It will take up some time and add another activity to your day.
- ➔ If the hospital has fluorescent lighting that gives you a headache ask if a family member can bring you a bedside lamp or other lighting from home. ●

TB TIPS:

BEING CURED OF TB

- ➔ The first priority is to take your TB or MDR-TB medication, then take steps to help you maintain your health and prevent a relapse. Like many people who have suffered a serious illness, you may decide it is time to change your lifestyle and make some positive improvements.

LOOKING AFTER THE HEALTH OF YOUR LUNGS

- ➔ If you smoke and you have had TB in your lungs (or anywhere else for that matter), this is a good time to stop smoking and give your lungs a helping hand. To be smoke-free is the biggest single step you can take to improve your health. Some people feel very breathless when they have TB in their lungs and smoking is the last thing they want to do. Use the experience of having TB to help you give up smoking.
- ➔ Speak to your TB doctor or nurse about any extra schemes available to help you to stop smoking. In some countries the health service gives out free

nicotine patches, inhalers or other pharmaceutical products that help with this.

EATING HEALTHILY

- ➔ It is possible to eat well on a budget but it can be difficult. You need motivation and you have to know what to select. Buy fresh foods regularly and check what the shops in your area are selling. Do not shop only at your local supermarket– it may be more expensive than other stores and the food may not be as fresh as in a specialty store or a local market. It is easy to get distracted by the large selection of less nutritious convenience foods in supermarkets. If you have a freezer, try cooking in bulk – it is very cost-effective.
- ➔ Eat foods such as those listed below. They are high in vitamins, proteins and other important nutrients that will help you regain a good nutritional status. This will improve your response to treatment and help prevent a later relapse of TB. If you are under-nourished you have a greater risk of developing the active TB disease. TB itself can lead to malnutrition. It is therefore possible that you may be under-nourished when you start the TB treatment. Healthy eating is part of getting better.

Beans
Branflakes (check label)
Dairy products
Eggs
Fish
Fortified breakfast cereals
Grapenuts
Green vegetables
Meat
Some soya milks
Wheat germ
Wholegrain cereals
Yeast extracts.

- ➔ If you have any questions, speak to a dietician.

- ➔ After a period of illness and/or being in isolation, you may want to go out and celebrate with your friends. Being able to socialize and drink alcohol again can be very tempting. However, it is important to remember that:
 - High alcohol intake after a period of weakness may affect your body's repair mechanisms;
 - Alcohol has no nutritional value and gives a false sense of energy;
 - Alcohol can affect your appetite and lower the levels of vitamins in your body;

A frequently high intake of alcohol may adversely affect the regularity with which you take your medication. ●

KEEPING FIT

- ➔ If you started to exercise in isolation, try and keep it up once you have been discharged. A brisk half-hour walk every day is good for your heart and lungs – if you can do more, all the better. Just be sensible about what is realistically possible. Also get plenty of sleep and rest when you need it. ●

TB TIPS:

AND FINALLY...

- ➔ Once you stop the treatment for TB or MDR-TB, you may have fears that the disease might return. You will probably still need regular check-ups at a clinic and your TB doctor may request that you have an occasional chest x-ray, sputum smear microscopy or other tests to ensure that TB has not returned and that all is well. Like everyone else, you may get a cold or flu from time to time, but be careful not to jump to the immediate conclusion that the TB has come back. It serves no purpose to worry unnecessarily. You must, however, be aware of how your body feels. If you have any concerns, simply provide your TB doctor with a phlegm (sputum) sample and he/she will be able to tell you definitively if the TB has come back or not.
- ➔ Be positive; look to your future and make plans. Like many difficult experiences, you may look back on this as a positive and life-changing time. You may want to think about how you can use your TB experience to help others. There is no end to the things that you can do – for example:

- ➔ Share your story with other people and tell them how you survived TB;
- ➔ Set up a “TB Club” or create a web site where people with TB can chat to each other;
- ➔ Start writing a newsletter for people with TB in your region; or
- ➔ If you are very ambitious, you could set up an organization where the voices of people with TB can be heard.
- ➔ After all that you will have been through, you will truly be an expert once you are cured! ●

ALWAYS REMEMBER

If you have TB or MDR-TB, you are never alone.