

## 5: CURE

*“Life isn’t finished for us yet! We’re going to live.”*

*(Anton Chekov)*

It is a wonderful feeling to finally walk out of isolation and into the world again. However, you may find that there are restrictions to your freedom with regard to social contact. Also, you will have to continue to take your medication correctly.

Your TB specialist will have discharged you feeling that you pose a minimal infection risk. This would have been established following several negative sputum smear results. Other criteria for discharge include absence of fever for at least a week and a degree of weight gain.

You may be asked when you leave isolation in a hospital to abide by some simple rules. In effect, isolation in the community. This means having social contact for limited periods of time as discussed in section 4. You will probably be required to attend the chest clinic at least once a month, and your TB specialist might put you on the DOT programme. He will also want more sputum samples so he can check that you remain sputum negative, and continue to monitor the cultures.

If you become sputum smear positive again, your doctor will re-admit you. This will happen if the medication is not working. This shouldn't happen if you are taking the medication correctly.

Do not assume that you have been discharged because you are cured. If you aren't being monitored by the DOT programme and you are having trouble with the medication, ask to join the programme.

Taking your medication is the first priority. There are other things that you can do to maintain your health and prevent relapse. Many people start to think about their lifestyle after a long illness and try to make improvements.

## **MAINTAINING A HEALTHY LIFESTYLE: DIET**

A healthy lifestyle with healthy eating habits is important for everyone. It can also be considered as a preventative measure to prevent latent TB infection becoming TB disease, and may prevent many other problems. After a period of illness, it is important to eat the right foods to aid convalescence.

Nutrition plays a key role in maintaining a healthy lifestyle. According to Jane Rowntree, senior dietitian at St. Mary's Hospital, London: "It is a very important issue; the body needs different sorts of nutrients to function effectively. A lot of people only look at their weight as a measure of how good their diet is.

"People may overeat and be overweight, but if they don't eat the right foods they can still be deficient in vital minerals. The overall picture of what people are eating is important. It's well known that nutrition can affect the immune system."

Eating meat and fish may be important in the treatment and prevention of the TB. Recently, a study of Asian immigrants in south London found that vegetarians who ate no fish, meat or dairy products were at least eight times more likely to develop TB

than those who ate meat or dairy products every day.<sup>1</sup>

The outcome suggests that a deficiency of vitamin B12 (provided almost entirely by foods from animal sources or fortified foods) increases the risk of developing TB. Appropriate intake is necessary to keep your immune system as strong as possible. A lack of vitamin D can also affect the strength of your immune response.

Jane Rowntree: “There are sometimes problems getting all of the nutrients you need. Vitamin B12 is concentrated in a lot of animal foods, such as milk, eggs and cheese. If you are a vegetarian or a vegan there may be a problem. It is important to make sure that you are getting enough before you develop any deficiency symptoms. If you don’t eat meat, fish or dairy products you can, for example, increase your intake of yeast extracts. These contain a high concentration of vitamin B12 and contain no animal by-products.

“High levels of vitamin B12 are found in some breakfast cereals. A lot of them are fortified with vitamins and minerals in any case. Regular consumption will ensure adequate vitamin intake.”

If your medication includes isoniazid or cycloserine you will be given a vitamin B6 (pyridoxine) supplement to counter some of the side effects. Some nuts are a good source of B6, but it would be difficult to get a large enough dose of vitamin B6 from food alone. Your doctor will ensure you get the correct dosage.

A simple solution is to take a multivitamin once a day. This will provide you with the recommended daily amount. It is important to note, however, that if you are planning any major dietary changes it is wise to consult a dietitian. Your doctor will be able to refer you.

## **KEEPING FIT**

If you started an exercise regime in isolation, try to keep it up once you have been discharged. You will find it beneficial, and it

may go some way toward convincing you that isolation was productive. A brisk half hour walk is good for your heart and lungs; if you can do more, all the better. It would be a shame to let all of the hard work in isolation go to waste.

## **SELF-ESTEEM**

TB and the isolation experience may have lowered your self-esteem. This is very common. To combat this, try to engage in activities that you know will increase your self-confidence.

Even small household chores such as the washing up can be fulfilling! In isolation, you have to ask for virtually everything that you need and have most things done for you. Doing these things at home makes you feel that you are in control of your life again.

If you have a job, and you are isolated in the community, try to work from home if possible using the telephone or the Internet. If you are unemployed, try continuing with or starting new creative activities. Don't underestimate the benefits of these.

## **POST-ISOLATION EMOTIONS**

You may have psychological issues to deal with after an isolation experience. There is no doubt that a period of isolation does affect people, sometimes in very subtle ways. Even crossing the road can be difficult. When you have experienced sensory deprivation in a small space where nothing moves, fast moving cars and buses can be very daunting. My suggestion is initially try to slow down generally until you find it possible to return to your usual speed. This is particularly important with any potentially hazardous activity: driving, operating machinery, cooking and so on. Take your time and concentrate.

After leaving isolation, you may wake up totally disorientated by your 'new' surroundings, especially on the first few nights at home. You may also find that you dream about being in the isola-

tion room, or have nightmares. This is a natural way for your mind to heal after a bad experience. If you are upset, talk to someone .

If you have an established relationship with a psychologist, psychiatrist or counsellor, then it is likely that you will probably see them again after discharge. Ask to see them if you don't already have regular appointments. Talk about how you are acclimatising to your new freedom, about sleep patterns, side effects and any other concerns you may have. One of the benefits of being on the DOT programme is that you will be building a relationship with whoever has been assigned to your case. It is likely that they will be able to offer you the benefit of their experience with regard to the problems discussed.

It is common to fear that the disease will return. Like everyone else, you may get a cold from time to time. Don't immediately jump to the conclusion that it's TB: this is easily done. It serves no purpose worrying unnecessarily. Be aware of your own body. Give your doctor a sputum sample, and he will be able to tell you how you are doing and allay your fears.

Look to your future and make plans. TB, like many bad experiences, can be turned into a positive life changing experience.

Eventually, the restrictions on your freedom will be lifted. The DOT will stop, as will the medication. You will still need regular check ups, and your doctor may carry out the occasional chest X-ray to ensure all is well.

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## **DIARY: FREEDOM AND CURE**

*Leaving hospital was traumatic. I couldn't live with my HIV partner anymore, and I left isolation without a real home to go to.*

**FRIDAY 13TH OCTOBER 1995** The brightness

of the outside world hit me. I had become used to seeing no more than 10 feet in front of me. All I had to look at were the plain walls of the room where I'd spent nearly three months in suspension between life and death. All of the movement of the 'real' world was overwhelming. I'd been asked to wear a mask on the way out lest there was a freak chance I may still be infectious. I'd become so used to seeing other people in them and now the role was reversed.

I sat down on a bench in the patients' roof garden. The daylight was so bright that my eyes ached as they tried to adjust. I lit a cigarette and tried to collect my thoughts. I hadn't reacted in quite the way I thought I would when (and if) the day of freedom came. For some reason, I almost didn't want to leave. There were so many restrictions in place.

I didn't know where I was going to live. I knew that temporary accommodation had been found for me at the last moment by the council, within 'spitting' distance of the hospital (pardon the pun).

I walked gingerly out of the main hospital building. I felt quite shaky. When I got to the main road, I took my time to cross safely. It would be tragic to end up back in hospital. I was disorientated; suddenly my world was enormous. In my hand I had a box of those masks - the only luggage I had.

I arrived on the doorstep of a large Edwardian house. It was in a little square of similar buildings. A car pulled up and a young woman introduced herself as my housing officer.

She had a few problems getting the front door open because of a pile of junk mail that had accumulated on the doormat. My new flat: flat 3.

It wasn't very glamorous. In fact, it was pretty awful but I didn't care - I was out of that room. I had left behind a comfortable life with my partner, and I would now have to 'ruff' it here. I didn't really own

a lot: I didn't have a knife and fork to eat with; I didn't even have any bed clothes, but I would manage somehow. This was freedom.

I had to go back to hospital for a brief chat with the doctor and found myself in the roof garden that I'd been in earlier. I begged the nurses to let me go there when I was in isolation, but the privilege had been denied. All three of the doctors, including the consultant, came to see me. Two of them were completely new to me: it was the first time I had ever seen their faces, having only ever seen them in masks. They looked very different to how I had imagined. I had sort of drawn in the rest of their faces in my mind's eye. I had been way off target.

We all sat together, as equals, without our masks. The weather was cooler than I remembered it. I had been admitted to hospital in the blistering heat of summer'95. Now it was autumn. I was given a final debriefing and the doctors and nurses wished me the best of luck for the future.

So, I walked out into it...

It sounds like the end of the story. It isn't. The terms of my discharge were harsh. I was not allowed to mix with people properly, only very transient social contact. I was unable to go to bars, restaurants or use public transport; difficult when you live in the city. I wasn't sure how to do everything that was expected of me and still feel free.

I was being housed by the homeless persons unit in a part of the city that I didn't know. In a way I felt more isolated than ever. The most important thing was that I continued my treatment. I certainly didn't want another term in hospital. The district nurse would come to see me once a day to give me my pills and injections.

I think, looking back, it was all a matter of being in control. For a time, I lost all sense of control over my future. Other people had been making decisions for me and I didn't like it. Any control I

could regain was another victory and another step forward. This even included cooking for myself.

When I moved into the temporary accommodation I had no heating or hot water. It was now late autumn and was getting colder by the day. In my room, I could see myself breathing in the cold air. One of the things I had really been looking forward to was having a hot bath. I had only been able to have cold showers in isolation.

Initially, I found it very difficult to cope. I wasn't used to doing things for myself. I had to really concentrate to do anything. Even using the telephone box around the corner was traumatic. Most of these feelings were probably due to the medicines. I hated them with a passion. Included in the varied collection of side effects caused by one particular drug was paranoia. Try telling a doctor that one: they tend to look sideways at you! One of the things I have learned is that many doctors don't understand the side effects of these drugs, particularly if these are psychological effects. In a way, this makes you feel more isolated. The feeling that others don't understand no matter how hard you try to explain. It leaves you with a sense of loneliness and futility.

Six weeks after discharge they found me a one bedroom flat. I was excited about this, but scared at the same time. I hadn't lived on my own for years and the prospect was daunting. Living on your own implies a freedom that I really wasn't used to.

The flat was a mess. In the corners of each room were heaps of old carpet. There was black dust everywhere from the decaying rubber underside of the carpet. It took ages to clean up and make the flat habitable. The first thing I did was redecorate. I needed to feel that it was really mine. It took time and effort, but I got there and I'm glad I did it. Gradually, I found - or was given - items

of furniture, and slowly a new home grew around me. For the first time I was thinking about something other than tuberculosis.

About a year later I met my new partner Mark, and he moved in. The restrictions of my isolation gradually lessened allowing me more and more freedom. My medication was eventually stopped.

## ~~TB TIPS: LIFE AFTER CURE~~

### ■ A HEALTHY DIET

It is possible to eat well on a budget, but it can be hard. You need motivation and you have to know what you are buying. Buy lots of fresh foods regularly and shop around! Don't just go to your local supermarket; they may charge more and the food may not be as fresh as from a dedicated store. It is easy to get distracted in supermarkets by less nutritious convenience food. If you have a freezer, try cooking in bulk. This is very cost-effective.

■ Eating foods high in vitamin B12 may help prevent TB.

■ These include:

■ *Meat .*

■ *Fish.*

■ *Eggs.*

■ *Dairy Products.*

■ *Wholegrain Cereals.*

■ *Beans.*

■ *Wheatgerm.*

■ *Green Vegetables.*

- *Yeast Extracts.*
  - *Fortified Breakfast Cereals.*
  - *Grapenuts.*
  - *Branflakes (check label).*
  - *Some Soya Milks.*
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- After a period of illness and/or isolation, you may want to go out drinking with your friends. Being able to socialise again will feel brilliant. However, 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. It can affect your appetite and lower the levels of vitamins in your body. Remember, a regular high intake may also adversely affect the regularity with which you take your medication.
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- If you have got any questions, ask a dietitian!

## EPILOGUE

Today my life is very different. It has taken time for the psychological wounds to heal. It was the most frightening, lonely experience of my life. I was ravaged both physically and mentally.

The disease is increasing in prevalence. We are no longer searching for a cure for TB: we have one. The problem lies with the length of treatment and the degree of commitment required. For those of you who have tuberculosis or have been on long term treatment, my message is a simple one: **Keep taking the pills!** There is life beyond this. I know that it's hard, but making the choice not to take them may prolong your own suffering and put others at risk.

As for me, life really couldn't be better. I have a new partner I love dearly, a home and a business. The whole experience has, in a strange way, enabled me to finally get these things. I appreciate life much more than I did. I have been given a second chance.

Having tuberculosis can be a lonely experience in a faceless environment. I am living proof that this disease can be beaten, and that you can lead a normal and often enriched life afterwards. As I said at the beginning, remember, you are not fighting this alone.