

What Does Someone Dying Need? **by Rex Winsbury**

When you get ill and are told you are going to die soon, needs come crowding in on you, jostling for scarce time and (often) scarce energies. So they in turn create their own need, a need for people and places to help you answer your needs. New needs then spring up as you begin to grasp the imperatives of dying.

"I was declared to be dying and did not. I experienced the needs and the challenges, and lived to reflect on them."

My position is odd - not unique, but privileged. I was declared to be dying, and did not. I experienced the needs and the challenges, and lived to reflect on them afterwards. A temporary reprieve, of unknowable duration. Those needs and challenges have not gone away, but I can now look at them with some benefit of hindsight. So I could sum up the needs of one person diagnosed as close to death, me, as being:

- The need to "settle up" with the people that I felt close to, so as to die in peace, with them and with myself.
- The need to have someone to "stand in" for me, to do what I could not do when I became helpless or consigned to the grave.
- The need for places and organizations that I could turn to for practical information.
- The need for someone to guide me, or go with me, round this new and unfamiliar domain of "the terminal state" - not necessarily the same someone for every sector of it.

Finances

I was lucky in having, already, an expert professional financial adviser who, as it turned out, could talk about death as a human being as well as help me plan for it as a financial consultant. I had also had the benefit, before my diagnosis, of talks with a psychotherapist, who had taught me something about the inner and outer processes of reconciliation.

Settling up emotional accounts

Settling up emotional accounts means going to those people who have been hurt by you, betrayed by you, misled by you, and not just asking forgiveness (because that is to perpetuate the desire to control the outcome by laying down what the outcome is going to be) but asking them to tell you how the hurt may be healed.

Once you have opened that door to them, given them that permission, you cannot control what will then happen. People will react in surprising, sometimes offensive, sometimes heart-stirring ways - but almost always in ways of their own choosing, which is the key to the success of this exercise.

The role of advocate

If you are ill, maybe in pain, perhaps drugged, perhaps even on life-support, someone needs to represent you to the doctors and nurses, the medical profession, to say what you would have said if you had been able, about your treatment, about where you want to live your last days and die, and what treatment you would (if you could) accept or refuse. This is about life-support; about pain; about dying with dignity; about relating your death to those who care about you.

I have a partner who would have played, and will play, that role with determination.

Drawing up an ethical will

An ethical (as well as a financial) will is a key document to have at life's frontier post. In an ethical will, you can say how and where you want to die, and in what medical circumstances. An ethical will help the person who "stands in" for you to argue the case with the doctors, and maybe the lawyers. It can say what sort of funeral you want. It can (if not done separately) give your last messages to those who matter to you. So here there are three stages. The first is to recognize the need for such a will. The second is to find advice on how to write one. The third is the most difficult - to actually write it. I dithered for months, afraid of the decisions implied in the clauses of an ethical will. But again, once done, it was a relief.

The funeral

Someone, if I have not done it already, needs to make my funeral arrangements, in accordance with the advice in my will, but subject always to the law of the land. Not everyone can cope with these last practicalities, which is why undertakers make a good living by applying a fixed ritual, and fixed price, to death. Some people care more than others about these post-mortem rituals, and how to redesign them in your own image. I myself care little, except to avoid more than basic expenses. Keep me from an expensive coffin.

One-stop-shop

I needed a place where I could go, there and then, if I fell ill again, if I began to die, confident that I would be known, understood, cared for, well advised medically, and listened to: somewhere I trusted, and where I would be treated as a full human being. There is a peace in knowing that there is such a place to go, if and when ... and that there is someone who will take you there.

Need to know

You need somewhere to turn to for basic information. Ignorance is the worst enemy. Some prefer ignorance, say it is bliss. It is not. Ignorance is the ultimate fright, the primal fear. Better to know what you are up against, know all there is to know about your illness, its treatments, the odds, the therapies, what others have done and said and suffered. But where is that place? Not everyone knows, or bothers to tell you. Just like a second opinion, knowledge can also be scary.

I spent a terrified afternoon in a bookshop, looking up the medical statistics about survival rates for people with my specific form of cancer. You cannot, must not wish that sort of knowledge on people who cannot cope with it. On the other hand, for those who grasp the power of knowledge, knowing the statistics can liberate you from the tyranny of being just a statistic.

A safe place to talk

Family and friends are often reluctant to face up to illness and death: even if they are not, their experience is not your experience, cannot be. So you may need, as I did, somewhere to go where you can talk, where it is safe to expose your inmost fears and terrors, your hopes and vulnerability. A group of people with similar vulnerabilities can provide that safe place, and be a powerful haven in which to bring out repressed feelings. They can support and share. But where is that group, and is it really safe? There are lists of support groups, but you may need help to get to one, even if there is one near enough.

Finding no cancer support group in my area, I started one. It has become a haven, both for me and for some dozens of others. I am sad that more people do not come to it.

Physical well-being

When your body is in danger, you need to do what you can to restore it, to prolong its utility, to seek to repair that wholeness that has been compromised by illness. Being diagnosed as terminally ill, does not always or necessarily mean that your physical activity has ceased, or cannot be prolonged. It is not too late. But where can you go to learn to repair what is damaged? Once again, this quest presupposes the will to do it, the same willingness that is inherent in many other felt needs, the willingness to plan for the future while knowing that you may not be there to see it.

But now, at the point of terminal diagnosis, more than ever, your need is to nurture your physical well-being by any means, to make the most of what you have left. But how? Exercise, diet? What exercise, what diet? Where is the place to discover this, and to do it? Probably, a conventional gymnasium is useless at this stage: hospitals are little use. Where can an ill person go to improve his or her physique? There are places, and which of them is a matter of knowing, and of choice, and the will.

I myself found great healing power, as well as physical exercise, in walking or jogging on Hampstead Heath, London, and in Chinese Qi Gong classes - both of these activities combine movement and meditation.

Guides and other special people

In addition to the financial and emotional advisers described earlier, I needed:

1. Someone or somewhere to talk about death.
2. Someone to tell me I am still beautiful.
3. Someone who would help to restore my hope, within the context of realism about my situation.
4. Someone to forewarn me and teach me about the stress of my illness upon others.
5. Someone to recognize and encourage the emergence of that new, alternative person that might never have been born without that illness and diagnosis: someone who will teach me to understand the power of the ill person, both over him/herself and over others - a power to be used wisely and humanely, for it can be, if misused, a tyranny, both over oneself and over others.

Epitaph

Having feared death all my life, now that I am confronted with it, I no longer fear it, only that the period leading up to death (a period whose duration, trickily, I do not know) will have been a waste. Had I during my life feared death as little as I do now, I would have dared more and better things. Only slowly is the power conferred by loss of that fear, growing upon me. Partly, this is because I am afraid of that loss of fear. Where will it take me? My final need is to find out that last truth. That is one need that, I suspect, no one else can help with.

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