



## Awaiting the Diagnosis<sup>1</sup>

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*It's a long walk, these five blocks to the doctor's office and yet not really long enough. My feet are moving and the surroundings are passing, but I have little awareness. My mind is numb with fear. I am aware of little else than the lump in my neck and the appointment I am about to keep.*

*Three months ago, my dentist noticed the lump and advised me to mention it to my physician "next time you see him." There was a studied naturalness about the remark. I remember contemplating it and saying to him, "You know, I'm a very healthy person, I seldom have need to see my doctor. Is this thing worthy of a special appointment?" His response was my first inkling that this might become serious: "Yes, you should see him as quickly as you can. In fact, I'll be phoning and talking with him today."*

*My family physician, Dr. Whitney, has an informal demeanor. I have always appreciated this about him. He palpated the lump and told me it did not feel like a malignant lump but we would do a number of investigations to find out "just what it is." I had a blood test taken that very day. The results were back quickly, showing I did not have leukemia.*

*The next test was a C.T. Scan. This was my first real contact with the technology of illness. I was alone in the room, lying on the hard surface while the machine groaned and hissed. Now and then a disembodied voice came through an intercom to tell me what I was supposed to do. I remember my heart thumping wildly and I wondered at my anxiety.*

*Waiting on the results of the C.T. Scan was my first taste of naked fear. The day I phoned about the results, Dr. Whitney's receptionist told me the results were back, then said, "Well ... he'll want to talk with you about this." The panic struck me like a punch in the gut and my brain was full of horrible thoughts. The three hours I waited to hear from Dr. Whitney seemed like an eternity. I was completely preoccupied with my terror. I filled the time with mindless activity. Driving home from work, I began to weep inconsolably because I was sure I would not survive to see my son grow up!*

*As it turned out, the C.T. Scan showed nothing. My relief was enormous, yet there was still no answer. Just what is this lump anyway?*

*I had been aware of the lump for about a month. It had not changed in any way (even though I daily willed it to disappear). Dr. Whitney suggested I go see an ear, nose and throat specialist. Dr. Robb.*

*My experience with Dr. Robb reaffirmed my fear and the continuing difficulty with not knowing. He looked in my ears, nose, and down my throat. He palpated the lump and said it did not feel like a "bad customer." Then he performed a needle biopsy.*

*I recall lying on the table in Dr. Robb's examination room awaiting the procedure. During his examination, Dr. Robb had said the lump felt like a cyst, and as I lay on the table I desired with every part of my being that the syringe would draw back fluid: "Oh, God, let this be over. Let it be finished right here, today!"*

*But the syringe did not draw back fluid. In fact I remember seeing the clump of tissue in the bottle as I left Dr. Robb's office. It was red and angry. Or maybe it was I who was angry. My neck hurt from the procedure. I felt invaded. And I knew I was not yet finished with the unknowing.*

*I had seen Dr. Robb in mid-December; therefore, the earliest I could call for the results was after the holidays, December 29. Over Christmas I tried to forget the lump in my neck, but I could not resist feeling it daily just to assure myself it had not changed.*

*When I called Dr. Robb's office on December 29, the receptionist said, "Oh, yes, Mrs. Ferguson, just a moment." She obviously went off to talk with Dr. Robb, returning to the phone to say, "Dr. Robb wants to see you. Could you come to the office today?"*

*At that moment I knew.*

*All the fear I had been struggling to hold at bay over the Christmas season came tumbling down upon me. My mind raced. I felt panic, dread, terror. I ran immediately to my husband who tried to calm me by persuading me there might be many reasons why Dr. Robb would want to see me. But I would not be persuaded.*

*And now, as I walk to my appointment, I hope upon hope that I am wrong, that my husband is correct. Once I reach the doctor's office, I am ushered in to see Dr. Robb almost immediately. He once again examines my nose, ears, and throat. Then he tells me he wants me to have an X-ray. He is filling out the necessary forms for the X-ray and telling me to return to see him afterwards. He is avoiding my eye contact. Finally I say, "Before I go for the X-ray, please tell me what the biopsy results have shown."*

*Dr. Robb takes a deep breath and sits in a chair facing me. The lump is malignant.*

## Waiting

I sit silently in the restaurant. I gaze about the room, noting the decor and the other diners. I think of the friend who will soon be joining me and I remind myself to ask her about her new job. I begin to read the menu. My friend arrives and smiles when she sees me. As she approaches the table, she says, "I hope you haven't been waiting too long." This experience of waiting has been in accord with the common definition of waiting: to stay in place, pause, remain stationary in expectation or readiness. We all live this kind of waiting—we wait for the bus, the doctor, the bank teller, the movie. In all these we have an expectation of a particular outcome and a certain sense of a reasonable amount of time for the waiting.

But waiting is not always a passive experience. In December, my seven-year-old son asks me daily, "How many days until Christmas, Mom?" When he hears the answer, he invariably responds, "Oh, I can't wait. I just *can't* wait!" It is such an exquisite anguish, this anticipatory waiting. And it is seldom passive. Much activity, talking, and thinking are brought to bear as we project ourselves into the longed for future.

In all these situations we have a definite expectation of the outcome of our pausing in time. There is even a fairly certain sense of the time that will be entailed in the waiting. The waiting allows us to prepare for the expected outcome. As I wait for my friend, I think of things I would like to ask her. As my son waits for Christmas, he anticipates the joys of that special day.

What is it like to wait when the expected outcome is uncertain? How is waiting experienced when the outcome has the potential to plunge the individual into the depths of despair? I remember one lonely night in the middle of a prairie winter waiting for my husband to return from a journey. As the hours ticked by in the darkness, long after his expected arrival time, I recall the desperation of my waiting. I envisioned him bloody and broken by the side of the highway, yet I struggled to convince myself that I was overreacting. When he finally arrived, safe and tired from battling the icy roads, my relief was a balm to my whole being. Because of the outcome, my life was not markedly changed by this experience. If the outcome had been different, the whole course of my life from that point onward might well have been altered.

Waiting on a potentially serious medical diagnosis is replete with uncertainty. The outcome is unknown. The length of time required to discover the diagnosis may also be indefinite. What is it like to live this particular experience of waiting?

## The Body in Between

Waiting on a medical diagnosis engages the body in a manner that is quite different from other experiences of uncertain waiting. Awaiting a potentially drastic diagnosis puts the body in limbo, a time of in between.

Does one begin to view the body as sick, or is it still well? This was especially dramatic for me because I had experienced little, if any, symptoms of disease. I felt the same as I had before. The only difference is the possibility of a frightening medical label being applied to me. It is that *possibility* that initiates changes in the body, or perhaps more accurately, how the self perceives the body.

During this in-between time, there are many aspects of life that reflect a healthy state. After all, in every way my embodied capacities are functioning as well as ever. I am not limited or impeded in any discernible way. But there are increasing aspects that reflect illness. It seems that the mere possibility of a serious threat to my normal embodiment has the power to take over my life in a manner similar to the experience of illness.

Holohan (1977) refers to this time as a “rite de passage.” Rites de passage are those experiences and rituals that accompany change of place, state, social position, and age. Is waiting for the diagnosis a rite de passage from the place, state, social position of well person to that of sick person? Is it a preparation, a dress rehearsal, for the changed person one may soon become?

One’s body is so integral to self. It is the way in which we encounter the world. In a state of wellness, we are not particularly aware of our body and its functions, yet our embodiment is so intimate a thing that when it is at issue all other concerns become secondary. This worried attention to the body diminishes the easiness of day-to-day life. Life goes on, tasks are done, but continually bodily concerns invade.

The lived body is not the instrument with which I act; it is my acting. On the other hand, it is the conscious vulnerability of the self in the world, the felt capacity to be affected, injured. (Gadow, 1982, p. 87)

Awareness of the bodily sign or symptom that originated the concern becomes acute. This unwelcome small lump has become me—it has taken over my life. Other bodily sensations now take on new dimensions. Does that cramp, that headache, that tiredness mean something sinister?

There is also the reaction to the violence of medical intervention. Is this necessary? I want to protect my body, protect myself from this invasion.

I am not ready to be labeled as diseased. I am not ready to take on the stigma of illness (see Sontag, 1978, pp. 26-36). Therefore, I try to carry on with others in my life as though nothing has changed. Although this allows a certain measure of normalcy, it requires more energy than previously because something *has* changed. I have a dark secret that isolates me from most others in my life.

## Desperate Waiting

Perhaps the most dramatic aspect of waiting for an uncertain outcome is the desperation. This desperation may only last a few hours, or even a few minutes, but it is so totally consuming that all else pales.

Despair comes from the Latin *desperare* (*de*—without, and *sperare*—to hope). Despair, then, means the loss of hope, the state of being without hope. Being desperate means being led, overcome, or directed by despair.

When faced with uncertainty that contains the seeds of darkness, the mind tries to make meaning. The emotions can easily hold sway, carrying one away with thoughts of disaster. During these moments or hours one feels trapped, captive to the terror of what might be possible. Nothing matters but the moment. The future is nonexistent. All of life is now.

Despair is in a certain sense the consciousness of time as closed or, more exactly still, of time as a prison. (Marcel, 1962, p. 53)

During desperate waiting, one does not sit idle, one *cannot* assume a pausing, stationary stance. The emotions flare and the body answers. There is need for physical action.

As I walked to the doctor's office, I was unaware of the walking. I saw only the grey sidewalk passing beneath my feet. A friend could have passed by and I would not have known. I felt totally isolated in my fear and dread. It took over my whole world. It was, for those moments, my only reality. I felt so small and vulnerable and alone.

But, even as the scenes of destruction tumble over themselves, there is a germ of rationality that begs to be heard. The little voice in my head insistently intrudes on my panic: "You silly woman! Get yourself together. There is no reason for you to despair just yet!" The rationality struggles to calm the emotions enough that hope may find an entrance.

The soul always turns towards a light which it does not yet perceive, a light yet to be born, in the hope of being delivered from its present darkness, the darkness of waiting. (Marcel, 1962, p. 31)

## Waiting with Hope

Between the moments of despair, the self opens itself to hope. Sometimes this is just getting on with day-to-day life, almost (but never quite) forgetting the question that is hanging there with no answer. Many times the mind reiterates the hopeful signs.

The lump hasn't changed, in fact isn't it a bit smaller today? Both doctors have said it doesn't *feel* like a malignant lump. I'm certainly not in a high-risk group for getting cancer. There are so many reasons to feel optimistic. I listen eagerly as my husband reiterates the reasons for hope (is he trying to convince me or himself?).

At this stage, though, my hope lies in the outcome being positive. This means that the lump is *not* malignant. I have not gotten to the point of seeing the possibility of hope even if the lump *is* malignant. So one could say that this is a somewhat limited hope, it has not yet become a part of my whole being—body, mind, and spirit. Perhaps that explains its fragility.

In so far as I make my hope conditional I myself put up limits to the process by which I could triumph. (Marcel, 1962, p. 46)

### Waiting with Uncertainty

Perhaps the theme that most poignantly flows through all aspects of waiting for a diagnosis is the unrelenting uncertainty. We human beings constantly project ourselves into our futures. I have a lunch appointment for tomorrow, there is a project I would like to have completed for next year, I pay into a pension fund. In big and little ways we plan and visualize the forward thrust of our lives. We *need* to expect and be ready.

Waiting for an uncertain diagnosis immediately creates an uncertain future. Suddenly, all the future projections we have made and are making are called into question. Rawlinson (1982) suggests: "illness confounds our capacity to expect. The future, either short-term or long-range, takes on a brittle quality. One finds one's plans disrupted and possibilities withheld" (p. 75). But I am still not sure that I am ill. To what degree is my future in doubt? In what ways should I be altering my future visions?

The not knowing creates a disequilibrium born not only of fear for my present well-being, but also for the future I cherish. In the definition of the word *wait* (Webster, 1989), one of the alternatives is "to be temporarily neglected or unrealized." Waiting, especially if it drags on, can have this effect. In the case of an uncertain outcome, perhaps the effect is even more encompassing, for it is one's future as well as the present that must be set aside.

As time passes, the need to know grows stronger. I am reminded of the many stories I have heard of people who have spent years of their lives going from doctor to doctor trying to find a label for a disturbing symptom. These people become increasingly desperate for an answer.

Yet there is an ambivalence—wanting it over, yet not wanting it over. The diagnosis marks the end of the waiting. Hope and fear are strongly intermingled as the diagnosis is contemplated. When the phone rings announcing the physician's call, I hesitate. But I do answer it. When it is time to go to the doctor's office, finally to get the word, I choose to walk rather than drive.

The diagnosis, the label I have been awaiting promises to bring with it a relief and release from these months of uncertainty. In so doing it may also present me with a challenge for which I am not sure I am prepared.

I go forth in dread. Yet the diagnosis must be known. My future must be decided.

### *Presentiment*

I am like a flag by far spaces surrounded.  
I sense the winds that are coming, I must live them  
while things down below are not yet moving;  
the doors are still shutting gently, and in the chimneys is silence;  
the windows are not yet trembling, and the dust is still heavy.

Then already I know the storms and am stirred like the sea.  
And spread myself out and fall back into myself  
and fling myself off and am all alone  
in the great storm. (Rilke in Norton, 1938, p. 79)

### Note

1. Excerpted from Ferguson, 1990.

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