



The Experiences of a caregiver

I'll describe experiences of family members who are either primary caregivers or primarily responsible for the well-being of a spouse or parent affected by Alzheimer's disease. These experiences have been shared with me by husbands and wives, as well as by adult sons and daughters in support groups and in private conversations.

In sharing these experiences, with you, I hope you'll better understand your own care giving situation and recognise the normality of your own emotional reactions. I also hope you'll feel less alone in your struggle to come to terms with what is probably the most difficult family situation you've had to endure.

Some of you have a spouse or parent who is only suspected of having Alzheimer's disease, or who has recently been diagnosed and is only moderately affected. If this is the case, you may find it upsetting to read about care-giving experiences at more advanced stages of the illness.

Though upsetting, the benefits of emotional readiness for future developments may outweigh the emotional distress evoked. For some, however, such readiness may not be worth the anguish and fear aroused. You may be better served by learning to cope with developments as they arise rather than reading about what may or may not occur in your case.

In this article, I'll focus on the material partner's experience of loneliness. I'll limit my focus further to experiences of loneliness during the caregiving period, in which the ill partner requires considerable supervision and care, but prior to the employment of extensive home care or nursing home placement.

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Going out Together

Prior to Alzheimer's disease, you took for granted that your husband or wife would accompany you for entertainment and at social events. Now you give considerable thought before going anywhere with him.

He may no longer be interested in or able to appreciate the entertainment, which you both previously enjoyed. When watching television at home together, you feel you're watching alone, because you know he's not experiencing what you're experiencing. What brings tears to your eyes leaves him unmoved; what makes you laugh leaves him unaffected. He may even shout at those on the screen, as if they were personally present. But whether your experience together is inside or outside your home, there is nothing to talk about afterwards, since he doesn't remember what took place in any case.

Going out with your husband, however, poses problems other than his inability to share your experience. Since he may no longer be aware of socially appropriate manners and behaviour, you always risk embarrassment. When dining out, he may eat with his hands or grab food from another's plate. He may emit strange noises or repeat bizarre movements. The attention this attracts makes you feel conspicuous and self-conscious.

Should he accidentally wet himself, you're not only embarrassed but feel awful for him as well. What can you do in public situations if he requires help going to the toilet? After all, he's not a child to take into ladies rooms. If he wears a diaper for incontinence, changing him is impossible. As a consequence, he's no longer a companion to go out with for entertainment.

Feeling Alone in a Crowd

Attending social gathering with your husband highlights the aloneness of you situation. Friends come up to say "hello" but after a brief interchange, leave and ignore you for the rest of the evening. They stay to avoid the discomfort of conversation with your husband. Even understanding this, you resent their unwillingness to spend more than a few minutes in a situation you live with all the time. You feel rejected and hurt, and more isolated and alone than if you had stayed at home.

The Dilemma of Family Events

When you're invited to family celebrations, such as weddings, graduations, or holiday festivities, you're conflicted about attending. If you take your husband along, you're afraid he'll disrupt the gathering by inappropriate behaviour. Besides, given your concern and responsibility for him, you wouldn't feel free to enjoy yourself anyway. And at any time he may become restless and demand to be taken home.

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If you decide to go alone, you feel guilty for depriving him of the stimulating experience of a family reunion. You're uncomfortable going alone anyway since you're so used to going together. If you resolve your conflict of going with him or going alone, or by not going at all, you resent him for depriving you of an enjoyable family occasion, even though you know it's not his fault.

Trapped by Dependency

If you're the only one at home taking care of him, going out alone is difficult for still other reasons. He needs you for everything. He calls constantly and follows you from room to room, even to the bathroom. If you tell him you're going out, he wants to know when you'll be back; but you know, if you say, "I'll be back in two hours," he'll expect you in ten minutes.

Even though you realize he's frightened when you're away, you nevertheless resent being trapped by his dependency. During the time you are out of the house, you imagine him impatiently waiting your return, and you're also worried about what he is doing. So while you're relieved to be out, he's still on your mind. How can you enjoy yourself feeling worried and guilty?

Of course, you could have more freedom if you hired an aide or companion to stay with him. But he objects. He doesn't understand why you need anyone and wants only you to take care of him. Besides, even you may feel taking care of him is your responsibility, not someone else's.

If you do have hired aides, and are free to go and come as you like, how do you fill your time? How many movies, museums and galleries can you attend? What's more, you usually have to go places alone since friends with husbands or jobs do not have the free time you do. Then when couples your age pass by, arm-in-arm, engaged in conversation, you're painfully aware of what you're missing and envy those who still have someone.

Feeling Abandoned

Couples usually relate and socialize as couples. If your husband is no longer able to relate or socialize, getting together with other couples becomes a problem. Also, Alzheimer's disease limits a person's ability to engage in the joint activities upon which friendships are frequently based.

Consequently, friends drop away just when you're most in need of companionship and if your partner is in a nursing home, few people think it appropriate to invite you alone.

More hurtful, however, is the distancing of family members. Your brothers and sisters as well as those of your husband may take no interest in your plight. Most hurtful, is if your own children show little concern with what you're going through. You then feel you have no one. Although you recognize your children have lives and problems of their own, you also know what you would do for them if they were in need.

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What you may be unaware of, however, is how painful their father's deterioration may be for them, and that they protect themselves by keeping a distance from both of you. Even knowing this, you're hurt and resentful.

No one understands

When friends or relatives drop in for a brief visit, your husband may remember conventional forms of address and appear relatively normal. What he says may seem to make sense to someone who doesn't know his reality. Then, if your visitor comments on how well he's doing, you feel no one really understands your loneliness in living with him.

Although friends and relatives may continue to ask "how is your husband doing?" They seldom, if ever ask, "how are you doing?" It is as if the only one to be concerned about is the person with the

illness – the caregiver is assumed to be all right. But there are times **you** need to talk to someone to unburden yourself, but you find few who are interested in listening for long. When a friend does listen, her life circumstances are so different than yours; she has little understanding or appreciation of what you're going through. Do not chase remaining friends away by boring them with your plight, you keep your feelings to yourself. You're then left feeling isolated in your aloneness.

The Loss of a Relationship

When alone with you husband you have no one to talk to, since he cannot carry on a conversation. You live in your own head, or say things to someone who is unresponsive. You also get no conversational stimulation from him since he says little or makes no sense. What's more, since he is unable to understand your thoughts and experiences, you have no one at home with whom to share your feelings. When you're upset or feeling blue, he is unable to comfort you, and when you're pleased or feeling good, he is unable to share your pleasure.

Most hurtful of all, is his lack of interest or awareness of you as a person. While you give so much of yourself taking care of him, he has little or no concern for you. If you're sick, he hardly notices, and if you tell him you're not feeling well, he soon forgets. What affects your life has little, if any, affect on him.

But **your** awareness of him as a person has also diminished. In the past, you knew what he thought and felt about himself and his life. Now you no longer know what goes on inside him. What he says makes little sense, even when his words are intelligible. Or he may speak only gibberish, if he speaks at all. In anguish you wonder, what is he aware of, what troubles him, is he upset by what has happened to him? You wish he were not aware at all then, at least he wouldn't suffer the humiliation and indignity of his affliction and you wouldn't suffer so much for him.

Although you both live in the same house, each of you lives in a different world, a world neither of you can share with the other. You feel more alone than if you lived alone. If he does not quite know who you are, or thinks you're someone else, you know you are really alone. You feel abandoned even though he is still there. You grieve the loss of a relationship, but your grief has no end.

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How can you stop grieving for someone who is still present and alive? In sadness and sorrow, you long for a relationship that was, but can never be again.

Opposite Sex Companionship

In losing your husband as a person, you're not only deprived of companionship, but may be deprived of physical and sexual gratification. While you may or may not fantasize about another relationship in which to satisfy these needs, the unavailability of appropriate persons of the opposite sex makes establishing such a relationship unlikely. But should the possibility of another relationship present itself, you may be tormented with soul searching questions. Can you continue

to be a responsible caregiver while enjoying companionship and physical intimacy with someone else?

Can you carry on a "double life?" if you can, do standards of fidelity make sense when your partner no longer recognizes you as his or her spouse? If you do become involved in another relationship, whom are you being unfaithful to, your partner of years gone by, or the person who thinks you're a stranger?

What will your children, relatives and friends think? Will they disapprove and accuse you of "abandoning" your ill spouse? Will you feel so ashamed that you go into hiding? Will you be plagued by guilt if no one knows?

One caregiver, in justifying an opposite sex relationship, described his material situation as a "medical separation". But only you can decide, based on answers to your own questions, what is "right" for you.

The Challenges of Loneliness

In highlighting the experiences of loneliness, I realize, you will not necessarily have all the experiences I've described. Some of you may have adult sons and daughters or other family members who are supportive and caring.

For others, old friends may continue to provide companionship. Those of you still employed may have meaningful relationships at work. Although your relationship with your spouse has changed, for some of you, the intimate physical care you provide may have engendered greater closeness than ever. Your devotion and care may have given your life new meaning and purpose, and enhance your sense of value as a person.

However, for many of you, getting the companionship and emotional support you need, is a major challenge. You may have to put forth special effort to acquire new friends to replace those lost. You may need to become involved in common interest and activity groups or join organizations whose cause or purpose you share. You may have to lower your expectations of others, so more people are acceptable as friends and companions.

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As you know, Dementia SA provides emotional support groups to help you feel less isolated and alone. Trained health professionals and caregivers who have experienced caring, lead these groups. Since participants in these groups experience situations similar to your own, they are uniquely able to understand your feelings. For many, the group becomes a supportive family and even engenders close and helping relationships outside the group.

It is important to keep in mind, that although you're not responsible for the disease, which has so changed your life, you **are** responsible for what you do or not to diminish your isolation and loneliness. You do not have to do it all Dementia SA is available to help.

**** For simplification, I'll henceforth effected to the spouse affected by Alzheimer's disease as "husband" rather than as "husband and wife."*

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