

## An Approach to Enhancing the Life Experience of Patients with Early Alzheimer's Disease

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### Opinion

It is not uncommon for people to later sever ties with family or friends they have cared for and had fun with when they were young. This severing may follow an argument that results in one or both persons feeling offended. As these persons near the end of their lives, however, they may, if asked to want to renew these ties.

This also may be the case when patients have early Alzheimer's disease. Then, however, care providers' inquiring and if these patients want this, then acting to facilitate this reconciliation is more urgent. These patients time to accomplish this re-uniting is likely, of course, to be less.

In this brief piece, I shall describe how providers seeing such patients may do this. I shall start with a case example involving a patient with who I carried out this intervention. The extent to which this emotionally moved her and gave her additional meaning in her life while, for her, both were still possible were marked, as I shall relate further, below, to say the least. I shall then refer to a small and very selected segment of the medical literature to suggest why provides might be warranted in anticipating that their inquiring and if wanted, then facilitating as I shall suggest, is likely to be beneficial, actually to both parties in most if not all cases. Finally, I shall discuss in more general terms the core, sequential steps that providers may take.

### An example involving a patient with early Alzheimer's dementia

When persons have early Alzheimer's disease, it may be even more difficult than usual to contact a long lost relative or friend to inquire whether they would be willing to at least meet once if not to reconcile after that. This may be more difficult for them for many reasons to on their own. Thus, care providers may most profoundly benefit these patients by taking the lead in this endeavor by asking them whether they might have an interest in trying to renew such severed contacts and then arranging for these parties to reunite if and when these patients want this.

I have been fortunate enough to have initiated and experienced this process with some patients both with early Alzheimer's disease and without this. These outcomes have been most gratifying for me, but much more importantly, and uniformly so, of course, for these patients.

I shall report here how I went about this, since how I did this may be useful to other providers wanting to pursue this same, most beneficial result. It hardly needs to be said that if a patient's illness has progressed too far, arranging this reunion may be more difficult or impossible. The patient may have more difficulty deciding what to say

when reuniting and, still later, may not remember this other person at all or as well.

Providers' awareness that such a patient had a childhood friend may simply come out spontaneously in discussion, or the patient may report this in response to the provider's specific questioning. If, then, the patient reports that this was a close relationship that it exists no longer, again spontaneously or in response to the provider's questioning, the provider can then ask the patient whether she might be interested in the provider's seeing if it is possible that they could reunite either in person or on the phone, even to just say, "Hello." The provider can point out that often people can change and change for the better, as former students, when older, often find when they later attend class reunions.

If the patient expresses an interest, the provider can then contact this other person, invite them, and add the following two points: First, the provider would be exceedingly grateful if this other person would be willing to reunite with the patient, in any way, because this other person's doing this for the patient would be, hopefully, meaningful to the patient in a way that the provider couldn't come close to herself. Second, if the prover feels, however, that a conflict is emerging, she will remover herself from the meeting then at once. This is because, she can explain, the provider already greatly appreciates this other person's being willing to meet and take this risk, but if then a conflict about new or old issues arises, the provider would not want in any way to support by her continued presence this other person's undergoing any further discomfort.

The providers saying this, while true, may to some other parties offer an implicit challenge- to take this risk and do all that is possible to see to it that this reunion succeeds. While this secondary effect is not the provider's intention, it may be a beneficial effect of the provider not wanting to be complicity in causing this other party greater harm.

The patient I am choosing to describe here with whom I did this hadn't seen her sister in three decades. This patient's sister was initially most reluctant to meet, but as I spelled out her sister's need and my, relative to this sister's, most substantial limitations, as I have outlined above, she agreed.

They met and interacted for about an hour. This patient's husband had driven this patient, his wife, to her sister's in a pick-up truck. I had driven myself separately. This patient was so grateful to me after this meeting that she climbed into the back of the pick-up truck to leave room for me next to the driver's seat.

This no doubt reflected some confusion she experienced at this time. She not so much later lost her ability to recognize either her husband or me. Thus, I felt exceptionally glad that we had made this trip when we did.

### **A framework suggesting that providers taking this initiative may help most patients and why**

The area of study most likely to give empirical support to this practice is the medical literature on the positive effects people may gain from forgiving. Forgiving to at least some extent may be necessary, of course, if patients, including those with dementia, want and are willing to reconcile and meet.

Self-reports and salivary cortisol levels have been one way in which the benefits of forgiving and reconciling have been studied. These measures have shown, for example, the success of an intervention carried out over weeks in an attempt to enhance the forgiveness and reconciliation among early married couples who had previously experiencing substantial conflict [1].

The gains of forgiving and reconciling have been studied using fMRI imaging. This measure has shown changes in brain activity in the precuneus, right inferior parietal regions and dorsolateral prefrontal cortex [2]. Biochemical changes also may occur. Neurotransmitters most likely to be affected may be, for instance, serotonin, noradrenaline, and oxytocin [3]

There are also, however, and not surprisingly, different degrees and stages of forgiving. Intending to forgive goes less far, than not only intending but then acting and when acting, by acting, one, emotionally too, carries forgiving out [4] Emotionally forgiving has, as might be expected, more direct and presumably more beneficial physiological effects than merely intending, as those affecting both persons central and peripheral nervous systems [5] Empirical study also has suggested that, psychologically, emotionally forgiving may generally be a necessary prerequisite to people being able to put behind that past wrongs of others so that they can then better forget these wrongs and go on freer and more as they want to with their lives [6]

This greater freeing up of their emotions may, of course, especially important and for this reason beneficial to patients with early dementia. In addition to the greater sense of inner tranquility and the greater joy accompanying their reconciliation memory, the greater freedom from past wrong preoccupations that this reconciliation can allow these patients to do more in their more limited, remaining time.

Providers could, of course also share this. If they do, they can also make clear that it is not their intent to influence the patient so that they do this or not. Providers can tell these patients that they are saying this and all else they say to be sure that the patient when deciding is fully and most accurately, beforehand informed.

### **How and when, more generally, providers can do this**

How then more generally might providers best approach and select approach these individuals?

There are basically two ways in which they might best bring this possibility of reconciliation up. They could do this more or less only passively. This would involve their principally waiting to see if patients happen to discuss with them their earlier lives. Then, if they do, by chance, mention an earlier time with a loved one they no longer see, the provider may say in response, then, "It sounds like you once cared for each other. Would you have any interest in my seeing if I could contact this person and arrange for you two to meet once again? If the patient says yes, they can then explain what is said above.

Providers can alternatively take an initiative that goes far beyond this. They can prime this pump, as it were, by asking such patients if it has

happened that they had loved ones in their past whom they once cared about but for a long time haven't seen. They can explain then why they are asking. They can explain that it is unclear how the patient's early dementia will progress. While it could get worse only slowly this is not always the case. Thus, the provider is asking about this past relationship, because it makes most sense at this time to see if the patient with this past loved one would want to unite.

With whom might a provider take these initiatives? The more passive initiative might be appropriate with any patient at any time. If providers are therapists, of course, it will be much more likely, that patients would report long lost loved ones as they describe their past experiences. If providers are not psychotherapists, they could, perhaps, still say this with any patient in a way that furthers the likelihood that they will benefit even more. They can say that if or since there is time, they wonder if they can share with the patient a question other have sometimes found important as a means to enriching their lives. The provider can then add that she is not at all saying this to suggest to the patient what he should do but feels that she must say this to be sure that in deciding what to do, the patient has additionally considered this.

The more active approach may, however, be a routine part of a provider's taking a history of every patient with early dementia. Though now not common and perhaps without precedents, this initiative may be particularly important with this group of patients. Unless the provider asks this, these patients' opportunity to gain from this soon may be lost.

An approach is described that may help patients with d early dementia reconcile with long lost relatives and friends with whom they once were close. This reunion may be beneficial to both parties.

It is important to note, however, in deciding whether or not to take these initiatives that this decision should not be based on the empirical question whether or not there is proof of these patients' gain. These interventions are based on the deontological value of showing these patients respect by introducing to them a possibility that they may not have thought of and thus that may increase their autonomy.

In this sense providers taking these initiatives is no different in principle from providers obtaining these patients' informed consent. A difference here, though is the rare and most exceptional meaning these patients can gain from having this opportunity.

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