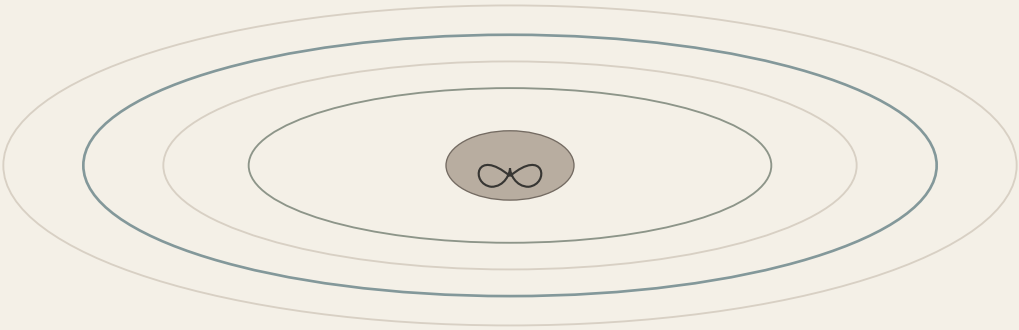
WHEN LOVING SOMEONE HAS TO LOOK DIFFERENT

A reflection for the changing shape of love



Love does not disappear when the relationship changes.
Sometimes it learns a different way to be present.

For the person living with dementia.
For the person who loves them.
For the Human Needs that remain in both.

BEHIND THE PUDDLE
Stasia Renfrow | behindthepuddle.blog

WHEN LOVING SOMEONE HAS TO LOOK DIFFERENT

A reflection on dementia, changing relationships, grief, and the Human Needs that remain.

There are kinds of grief that arrive after someone dies.

And there are kinds of grief that begin while someone is still very much alive.

When someone we love is living with dementia, the losses rarely arrive all at once. They come in pieces.

A conversation that no longer happens the way it once did. A familiar expression that appears for just a moment. A shared routine that becomes difficult. A visit we looked forward to that leaves everyone unsettled. A person who knows us one day and seems unsure of us another.

And sometimes, one of the hardest changes of all: learning that our presence may not always bring the comfort it once did.

That can feel almost impossible to reconcile with love.

We spend our lives learning that love means showing up. We visit. We help. We stay. We reassure. We remind. We fix what we can.

Then an illness such as dementia can change the rules without changing the love.

There may come a time when visiting less is kinder than visiting more. There may be moments when explaining creates more distress than understanding. There may be days when the person we love responds to us with fear, anger, suspicion, agitation or indifference.

None of those things fit comfortably inside our understanding of what a loving relationship is supposed to look like.

And yet, the relationship is still there. It has simply entered territory neither person chose.

The Human Needs Remain

One of the things I have been thinking about lately is how remarkably persistent our Human Needs are.

We need to be seen. We need to be heard. We need to belong. We need to matter. We need to remember and to be remembered. We need to be welcomed and accepted. We need to be understood. We need to be loved. We need to be witnessed. We need to have a place.

Dementia can make meeting those needs more complicated, but it does not make them disappear.

A person may no longer be able to tell us, "I need to feel safe." They may show us instead. They may not be able to say, "This is overwhelming." Their behavior may say it for them.

They may not recognize the person standing in front of them while still responding to gentleness, familiarity, music, warmth, quiet or touch.

Sometimes being heard means listening to behavior instead of words. Sometimes being understood means accepting that their experience of the moment is different from ours.

Sometimes loving them means no longer requiring them to understand our love in order for that love to be real.

That is an enormous adjustment.

But There Are Two Humans Here

This is the part I think we sometimes forget.

Dementia does not happen to only one human being. There is the person living with the disease. And there are the people who love them.

They still need to be seen, too. They need someone to notice how lonely this can become. They need to be heard without immediately being given advice.

They need somewhere they can admit: "I don't want to go today." "I desperately want to go today." "I miss the person who is sitting right in front of me." "I am angry." "I am exhausted." "I feel guilty when I am there." "I feel guilty when I'm not there." "I don't know what the right thing is anymore."

Those sentences do not mean there is less love. They mean there is a human being trying to carry something extraordinarily complicated.

They need to belong somewhere beyond the role of caregiver. They need to know they still matter independently of how well they manage someone else's illness. They need to be welcomed into conversations where they don't have to pretend they are doing fine.

They need to be understood when grief and relief somehow occupy the same afternoon. They need to be witnessed. And perhaps most importantly, they still need to have a place in their own life.

When Presence Changes

I think one of the cruelest assumptions we can place upon ourselves is that love can be measured in hours.

How long did you stay? How often did you visit? Were you there enough? Did you do enough?

But perhaps those aren't always the most useful questions.

What does love need to look like today?

Today it might mean sitting beside someone. Tomorrow it might mean allowing them to remain settled. It might mean talking. It might mean silence. It might mean holding a hand. It might mean trusting the people caring for them when they tell you that something different would be kinder today.

And sometimes love means going home.

Going home does not mean leaving someone behind. Resting does not mean forgetting them. Laughing does not mean you have stopped grieving. Having a good afternoon does not betray the person having a difficult one.

And building pieces of a life around an enormous loss does not mean the life you shared mattered any less.

There May Not Be a Perfect Way to Do This

We like instructions because instructions suggest that somewhere there is a correct answer.

But relationships have never worked that way, and dementia certainly doesn't.

There may only be the best decision available in this particular moment, with the information we have and the capacity everyone has that day.

That is a much gentler standard than perfection.

Perhaps the work becomes less about preserving the relationship exactly as it was and more about honoring what still exists.

Love still exists. History still exists. The life that was built together still exists. The stories still exist, even when only one person can tell them.

And the person who remembers carries something precious - but they should not have to carry it alone.

Touching Base With the Human Needs

On especially difficult days, perhaps there is a simpler place to begin.

Not: Am I doing enough?

But: What Human Need is asking for attention right now?

Does the person I love need safety? Quiet? Acceptance? Comfort? Someone willing to witness this moment without correcting it?

And then another question that matters just as much:

What Human Need is asking for attention in me?

Do I need to be heard? Do I need companionship? Do I need rest? Do I need someone to remind me that I still have a place in the world outside of this illness? Do I need permission to miss what was? Do I need to laugh today? Do I simply need another human being to sit beside me for a while?

There doesn't have to be a profound answer. Sometimes identifying the need is enough.

Because the person with dementia remains a whole human being. And so does the person who loves them.

Neither one's needs erase the other's. There is room for both.

Maybe that is one of the things we can offer each other when there are no solutions left to offer: a place where love is allowed to change shape without being questioned; a place where grief doesn't have to wait for death; a place where guilt isn't mistaken for proof of devotion; a place where the person living with dementia is still seen as a person rather than a diagnosis; and a place where the person standing beside them - even when "beside them" sometimes means being somewhere else - is seen, too.

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A reflection for families and those who walk beside them. This piece is educational and reflective in nature and is not a substitute for individualized medical or caregiving guidance.