

On Film and Digital Media

It Does Not Have to Be This Way

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After Anthony Hopkins won the 2021 Oscar for best actor in *The Father*, our Dementia Together team viewed the film and found it creatively compelling and hopelessly heart-breaking—everything the cultural “tragedy narrative” around dementia would have us believe is inevitable and true.

As we watched *The Father* and wondered, “Wait, what? Did I miss something?” we experienced the greatest brilliance of the film in showing us what it might *feel* like to be confused about recent facts without having a companion alongside us, in what the SPECAL (pronounced “speckle”) Method calls a “We-Relationship.” This UK-originated, person-directed method, based on the SPECAL Photograph Album analogy, is an example of an approach that enables “living well with dementia.” The analogy offers us one way of understanding how someone with dementia might be experiencing reality and shows us how we automatically reference recent facts in order to manage throughout our day.

The analogy very simply explains our memory system as a photograph album with each of our individual memories stored as photographs in our album. Each photograph contains the facts and associated feelings of what has just occurred (Figure 1).

Photographs are arriving automatically and unconsciously all the time in our albums, providing us with information about the facts of what we have just been doing and how we have felt about it (Figure 2).

With dementia, the experiences continue to store as photographs, but not necessarily with the facts of what has just occurred. Instead, the dementia-related photographs store as fact-free, feelings-only photographs which we call “blanks”—meaning blank in terms of facts (Figure 3).

“Today’s page,” like other pages in Anne’s photograph album, shows facts and feelings storing coherently. Compare that to “Today’s page” and other *current* pages in

Anthony’s album where photographs are storing, randomly and intermittently, as feelings-only blanks (Figure 4).

Just as we witnessed in the movie, the blanks are stored with increasing frequency, until today’s page is storing only rare normal photographs with the facts and feelings amidst a sea of blanks in which the feelings of an experience take up all the space where the facts would have normally been stored.

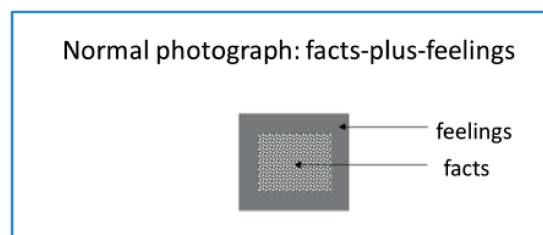


Figure 1. Normal photograph: facts and feelings.

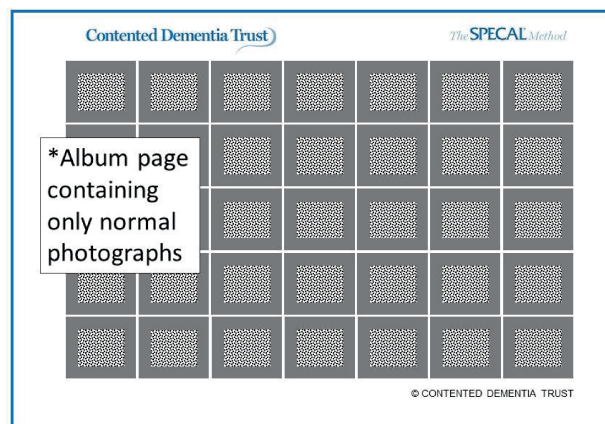


Figure 2. Album page containing only normal photographs.

Watching the film with the SPECAL Photograph Album in mind, we can “see” Anthony’s stressful searching in his album for facts he needed to give him context for what was happening in his life. With or without dementia, we do not “just know” things. We continually and automatically check our albums for factual information required to make sense of what is going on in our lives, to be able to answer questions, and to figure out statements that challenge what we thought was right. Anthony did not lose his reasoning capabilities or his desire to reason. He has simply lost recent facts with which to reason.

Because the image of Anthony’s album was flashing in my mind while watching *The Father*, I counted 11 times that Anthony was asked, “Do you remember?” or “Don’t you remember?” I tallied an additional 71 times when other direct questions were asked of Anthony—questions he could not answer because he did not have available facts stored in his album. Logical explanations were given 20 times with the assumption that recent facts were storing for Anthony. Clearly, they were not. Therefore, logic and common sense were not helpful. Anthony was contradicted 17 times, forcing him to consult his “album” each time to try to figure out why, coming up with no factual explanation but only a feeling of frustration. This, in turn, led to more blanks filled with anxious feelings entering and

storing in his album until, to the surprise of his unknowing companions, Anthony expressed an outburst of anger.

The saddest part of the film was that no one even knew that the hopelessness they felt was unnecessary. Just because someone loses the ability to store recent facts does not mean they lose the ability to experience, enjoy, and even savor moments. Changes in the mind for anyone with dementia simply mean we, the people without blanking album pages, need to shift the way we communicate so that we can connect in meaningful positive ways.

I have rewritten *The Father* in my own mind with Anne doing dementia care differently—embracing creativity, kindness, and counterintuitive strategies like avoiding direct questions (since direct questions may very likely create the anxiety of not knowing the answers because the facts were not stored). When companions learn how to create a “We-Relationship” with Anthony, the ending changes. Anthony is content. He is no longer so traumatized and afraid that all he can do is cry out for the security of his mommy. Instead, Anne and the care team are listening to Anthony for clues about how he is coping with his blanking album, discovering what is important to him at any given moment. They spot details like Anthony’s pride in Lucy’s artwork, the importance of his watch as a security object, and even how Anthony does not like Paris because “they do not even speak English there.” Anthony is enabled to make sense of his world without having to answer questions or agonize over contradictions (searching for facts that are not stored). He is engaging in joyful conversation with his companion as they admire Lucy’s beautiful painting or the intricacies of his watch and maybe even chatting about the ridiculousness of anyone wanting to go to Paris because “they do not even speak English there.”

In the “SPECAL version” of the film, Anthony and Anne still experience life absurdities. Their lives are not perfect. Life without dementia was never perfect either. Their lives are, however, good. They are filled with purpose, laughter, beauty, joy, and hope—not hope in a future cure, but tangible hope in the current care that sustains well-being.

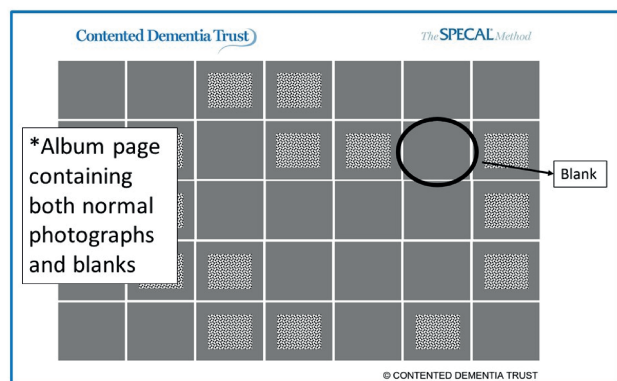


Figure 3. Album page containing both normal photographs and blanks.

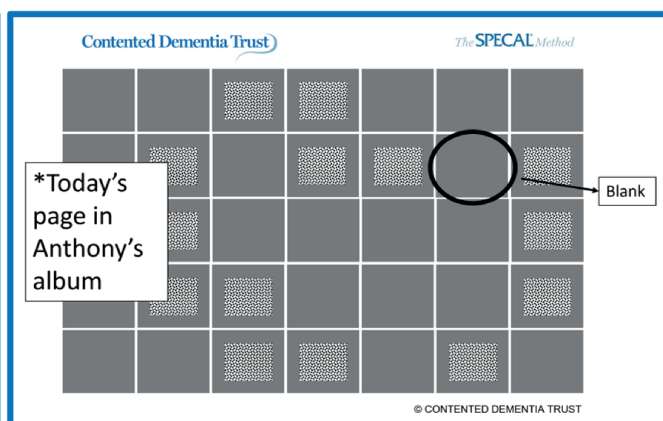
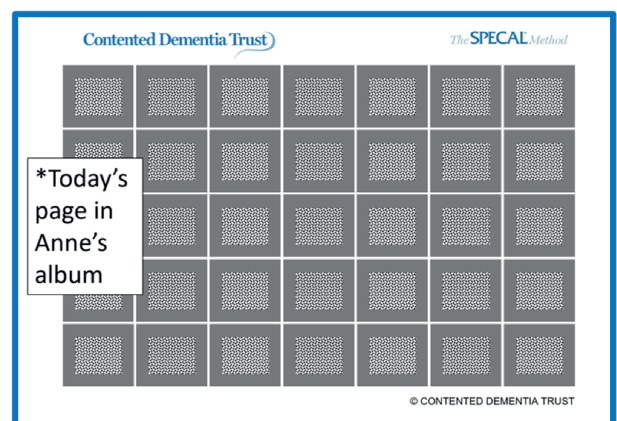


Figure 4. Today's page in Anne's album and Anthony's album.

The key to contentment is dementia care that lets the person with dementia lead the way. When we listen carefully to the person experiencing dementia, we make “living well” with dementia the expectation and not the exception. Together, we can all retire the tragedy narrative and rewrite better stories.

Author Note

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