Dear Ask Pact:

Our staff keeps asking how they’re going to make this culture change thing work with those who are bedridden, are severely contracted, or unresponsive. They can see how it’s all meaningful for our active community members, but they focus their concern on the smaller number of people with this level of debilitation. Any thoughts on that?

I’m going to try to start up a focus group on this very thing, but I know they’ll need something to jump start them. Any ideas?
- Mark

Dear Mark:

Mark, this is a question we hear all the time. It is interesting to me for a number of reasons.

First, though you have created ‘home’ and a sense of ‘family’, I assure you, that small group of staff will not be satisfied, will not sleep well at night, until they figure out the answer for the person(s) in their neighborhood that is lying in bed. The wonderful thing is that at that point there will be an entire team - caregivers, professionals, families - that will try to figure out the answer for the elder that needs special attention. And it will be far more effective than a care plan!

Person-centered care is extremely attentive to this situation. Think about it: whom do we ignore in the traditional setting? Whom do we begin to think of as more of an object? The quiet, the non-responsive, and the bedridden.

The person-centered philosophy says: “I am a person also, lying here; reach me, touch me, love me.” When we reach out to these elders, it can be very powerful – you will see magic happen! You’ll hear dramatic stories of a tear on the cheek, a hand moving, a tight grip, or a soft “thank you.”

The story I tell to exemplify this is of a group of elders on a small team with staff working to learn about daily pleasures. They divided up the elders in their neighborhood and began to interview them. One resident had been very eager to interview a non-responsive bed-ridden fellow. She said she had thought a lot about him, every time she passed his room, and wondered about his life. Other people were confused (how could she...
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'Interview' him?) but were relieved that she had volunteered.

She went to see him and came away and told this story. She said that she told him what the team was doing. That they cared and wanted everybody to have a few minutes of pleasure every day – as they always had at home. That for some, that meant coffee in their pajamas, for others it might mean music in their room, or a chance to go outside every day. She told him that she was a resident, and that her daily pleasure has always been to talk to people and to connect with others. And so she had jumped at the chance to come and talk to him about his daily pleasure. He did not reply, but she sat with him. A little while later, she prepared to leave. His hand was just a few inches from her and as she started to stand, he reached over and put his index finger inside the cuff of her sweater, restraining her in the slightest manner. She turned to his face and tears were streaming down. She had found a new friend, someone she could be with every day for a few minutes, deepening her pleasures in daily life, and certainly his.

Please feel free to print this out and share it with staff. Encourage your staff to tell stories of miracles that they have already seen in their work lives. The stories are out there, even in the traditional world, of miracles of connection, relationship, and person-centered care for the severely disabled. Help your team discover them amongst themselves, and they will quickly realize their own power.

Perhaps hand this letter out before a learning circle, let people read it - then begin the circle with each person sharing a thought or feeling. When you open for discussion, ask who has experienced one of these miracles with the quiet elders who live in their beds and with minimal communication. Ask them to tell their story. After a few stories have been told, ask the group - who, of our residents, worries you the most? Then move to a discussion of what can we do to bring a few moments of pleasure each day to that elder.

Yours Truly,

A. Pact