

Melissa Schebloom

Good Morning. I want to thank you all so much for being here. As a social worker, serving individuals and families facing this disease, as well as a caregiver to my father, it means a lot to see so many people in here today investing their valuable time and energy to pave a new path towards quality care.

Rodolfo's summary is the sad truth and is a story I hear daily from the families I serve. These stories also mirror the situation that my family found ourselves in when discovering my father's diagnosis. The delayed diagnosis, complicated referral process, failed attempts to navigate through the system, and lack of follow-up care is an all too familiar scenario for families battling this disease. Individuals and families are left feeling lost, confused, frustrated, and alone. If this is the common experience of the clients and families facing this illness, I think we can see that the system is not working. This is not quality care, and we can do better.

There are so many obstacles when addressing the complex needs and barriers that our clients encounter. At times the task seems too big to tackle or even hopeless. But we can't let these barriers stop us. We might not have all the solutions any time soon, and I imagine that new challenges will surface along the way. But change is possible and it starts with action.

In my experience as a caregiver to my father, as well as in witnessing and supporting the families I work with on this journey, I often think about what could be done to improve the current system. I have a wish list of sorts, that in reflecting on what I have seen and experienced thus far, seems could help clear the fog a bit while clients and families navigate the care needs of this difficult illness. These wishes include required training, education, and built in tools to professionals in regards to early detection and follow-up care. This includes providers being experts in providing a compassionate diagnosis, including quality education and referrals to community based resources, and lastly but not least this would include a standard for follow-up care and case management across all health care facilities, employing more well trained and experienced social workers, care coordinators, and community health workers to follow-up and provide community support to clients and families.

- 1) As many here have mentioned, early detection is huge. I see this improving greatly over the years, but it seems we still have a long way to go. Additional training is crucial to both medical and mental health providers, social workers, care coordinators, and community health workers. There should be a standard operation for screening with readily accessible tools, in which professionals are trained to use in order to do so. However, I would like to pay special attention to the importance of how a diagnosis is communicated. Many of us were told of this diagnosis vaguely, without consideration if it was understood, and without discussion of how to access or understand additional care needs. For many families the word dementia or Alzheimer's comes with little to meaning, or if there is meaning it is attached to strong stigmas and fear. Providing a compassionate diagnosis with the delivery of quality education and a clear pathway to resources should be the standard. Telling families that you are in this with them, giving them a direct number to call with questions, and providing them with some idea of what to expect could mean a world of difference to how they leave that office, what meaning they attach to this illness or how they cope moving forward. Maybe something as simple as saying it is normal that you will be bombarded with a million emotions over the next few weeks, months, years. This is normal. I am here with you and this is who you can talk to, this is who you can call, here is where you go for help. And before you leave today let's get you scheduled for a follow-up

- 2) I have found that this idea of follow-up care and case management is so incredibly important to support families and to improve the quality of care of clients with dementia and Alzheimer's. It seems to me that a follow-up with a medical provider within a short time period should be the standard, at which time clients would be encouraged to bring family members if available, and during which time additional support and education would be offered, as well as referrals for long term care consultations, home care, and additional community supports. Ongoing follow-up visits should be part of this standard, offering guidance and support through the different stages of the disease and the different challenges that will inevitably surface.

- 3) In order to offer this level of care, facilities need to have additional staff on site to meet this demand. Often times clinics and hospitals are understaffed, leaving one or two social workers to cover all the social service needs of the clinic. Additionally, medical providers have short time slots to meet with clients and the families, making this idea of quality compassionate care nearly impossible.

To sum this wish list up in conclusion we need longer visits, more support staff, better training, standard tools for screening, and a high expectation for follow-up and case management. In doing so I believe we would see better quality of life for those battling this illness, less crisis situations, better health of patients and care givers, and less frequent hospital visits. This is a wish list I know but not impossible.

Thank you again for your time today. I know it seems overwhelming to think of all the changes and developments that need to occur, however any change is possible if we can acknowledge what is currently going wrong and commit to take action. Thank you. Have a good afternoon