

# Words Matter

THE DEMENTIA SHERPA'S  
GUIDE TO

## Dementia-Friendly & Preferred Language





# Cheat Sheet #2

Referring to a person as what they are--a person--is always okay. If you don't know their proper name, or want to describe the person as well as the condition or situation, here are some preferred ways to do it.

## NOT OKAY

- Victim
- Sufferer
- Demented
- Problem
- Difficult
- Crazy
- Manipulative
- Behavior problem
- Whiner
- Complainer
- Screamer
- Aggressor
- Wanderer
- Attention seeker
- Empty shell

## OKAY

- Person living with [diagnosis]
- Person living with [diagnosis]
- Person living with dementia
- Person with a request/unmet need
- Person with a request/unmet need
- Person with a brain illness
- Person with a request/unmet need
- Non-verbal communication
- Person with a request/unmet need
- Person with a request/unmet need
- Person in pain/has unmet need
- Person who initiated contact
- Person looking for something
- Person with a request/unmet need
- Person with advanced condition/in late stage disease process

# Preferred Terms

## REFERRING TO AN INDIVIDUAL OR GROUP:

- Given name/group name (eg, Frankie Valli or Frankie Valli and The Four Seasons)
- Person/people
- Person/people with dementia
- Person/people living with Alzheimer's
- Person/people diagnosed with Lewy Body Syndrome

## REFERRING TO A SETTING-SPECIFIC INDIVIDUAL OR GROUP:

- Client(s) are customers of professionals. Dementia Sherpa has clients.
- Resident(s) live in a certain place. Rolling Hills Memory Care has residents.
- Patient(s) are seen in a clinic or hospital. Dr Sidhu has patients.
- Participant(s) are part of an activity or program. Providence ElderPlace has participants.

## REFERRING TO WHERE SOMEONE LIVES:

- At home
- Proper name of community
- Residential care
- Care community
- We don't use the f-word! Facilities are buildings where people work, not a place where people live.

# True Story

Several years ago, I picked up the phone to a professional wondering if I was accepting new clients. About 20 minutes later, I got a call about the same potential new client, this time from a family member.

These are the words they used to describe the person:

- Princess (not in an admiring Diana kind of way)
- Pain in the ass
- Difficult/Demanding
- Whiner
- High-maintenance
- Liar
- Incapable of happiness
- Impossible to please
- Unreliable reporter
- Chronic over-user of resources
- Hysterical
- Delusional

I mean, who wouldn't say, "Heck, yeah!" to all that?

Some better questions are:

Would you want to be around this person?

How do you think that description would affect your mindset about this person? About how you interact with this person?

But what if.....

# True Story

What if the potential new client had been described this way instead?

- Used to being in a position of authority/power as a highly respected professional
- Assertive and persistent; doesn't take 'no' for an answer
- In search of solutions and discerning about who she works with
- Prefers to have a notebook with her for appointments
- Currently being treated by 8 specialists
- Laser focused on resolving current health concerns and becoming frustrated with lack of results

Sounds reasonable, doesn't it?

In fact, this person had been misdiagnosed. It took a great deal of persistence on our part to get to the right diagnosis.

No one should have to hope that the stars line up in just the right way in order to get the assistance they deserve. No one should be called names, stripped of their dignity, or treated as less than because of a medical condition. (Or any other reason, frankly.)

So if someone tells you it's just words, or not to worry about being so PC, feel free to share the story of just one example of why words matter.

Questions? Comments? Suggestions? Email [Christy@DementiaSherpa.com](mailto:Christy@DementiaSherpa.com), or DM at [Facebook.com/DementiaSherpa](https://www.facebook.com/DementiaSherpa) or [Twitter.com/DementiaSherpa](https://twitter.com/DementiaSherpa).