Quotes about Leisure from Persons living with Dementia

“They think I can't do anything. Until they get used to me and what I can still do many try to take over. Also gave meaningless activities like tip all the pens and pencils out on the table, mix them up and then ask us to sort them out. That made me angry. One care worker accused me of lying when I talked about being involved on a consumer committee because she said that if I had dementia I couldn't do it”.

“They don't take the time to know my own personal interests, want to herd me into group activities that are simple, cheap, and require no individualized contact. It pisses me off, demeans me”.

“They introduce child-like activities and put all of the participants in one category”.

“Professionals assume that learning new stuff would be very difficult for me. This makes me feel that I may have some limitations but that doesn't mean that my life has to stop”.

“The tendency is to believe leisure activities are easier than work activities. I get annoyed at being discounted”.

“Why is it we get out of bed in the morning? What drives us to open our eyes and engage the world around us? Despite what others might think, I have aspirations. Every human being, driven by the nature of being a human being lives in a world of their own aspirations. I want to and am determined to achieve some things”.

“Many think it is the disease that causes us to withdraw, and to some extent I believe this is true. But, for many of us, we withdraw because we are not provided with meaningful opportunities that allow us to continue to experience joy, purpose, and engagement in life”.

“I’ve lost access to the tools that helped me feel good about myself. No job plus no driving, plus few friends multiplied by little or nothing to do other than activities I don’t want to do equals a purposeless life and day to day an increasingly minimal and un-stimulating existence”.

“Too many professionals try to take too many things away too quickly”.

“I, like all human beings, must live in today. You come and reminisce with me. You show me pictures, movies, things. We talk about the “good old days.” Then you leave and I am left in today… Reminiscing is good. Reminiscing is fun. But it is an activity that does not support living in today, nor realizing my purpose today. Use it sparingly… for a fun activity after the purpose-filling activities have ended. Use it as a means to an end; an end to help me stay in, to fully understand and appreciate today. Use it to remind me of my accomplishments and the life I have celebrated. But help me to continue to live my life today, to have accomplishments, meet my aspirations, live a future, have things to look forward to and celebrate now”.

“Without my involvement in the process, others cannot find a new sense of purpose that fits for me. What they begin to substitute then is activities. How many of you can’t wait to be old enough to play bingo? Somehow we believe that when you’re old, you can’t wait to play bingo, not once but every day of the week. We need to work on this task together. We need to be creative together. We need to identify the elements of what I like to do. What makes me smile, feel good about myself? What is meaningful to me? How can I get and do more of this? What kind of tasks must be collected or invented to meet my new found sense of purpose? I can still grow and learn. I can still contribute”.