

CONTENTS

For the Caregiver: When the Patient's Personality Changes

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Brain tumors can bring about personality changes in the patient, which puts extra burden on the caregiver, who must cope with unexpected changes in his or her loved one.

"Caregivers can be unprepared for the changes in mood and behavior that the patient might experience," says Natalie Lucchesi, a social worker with the American Brain Tumor Association. "It can be quite a shock."

For the most part, the extent of change depends on the size, type, and location of the tumor. The frontal lobe is the command center of personality, so tumors in this locale cause obvious behavioral changes. Pituitary tumors create hormonal imbalances that affect mood, emotions, and sex drive. Even a tiny tumor in the speech center on the left side of the brain can profoundly affect language and the ability to express emotion.

"A brain tumor patient that has lost their speech might desperately want to tell a grandchild how much they love them, but not be able to get the words out," says Minesh Mehta, MD, of the University of Wisconsin. "You can imagine the frustration and trauma that brings upon them and their families."

Some treatments exacerbate rather than relieve the problem. Surgery can further damage speech or memory centers, and radiation can produce sudden personality changes because of swelling and long-lasting effects on memory. Plus, many treatments cause fatigue that can turn a former go-getter into a couch potato.

Every patient's reaction is unique, as is the solution.

Lucchesi recommends patients and their caregivers consult a neuropsychologist who has experience with brain tumor patients. The neuropsychologist performs tests before and after treatment to determine what parts of the brain were affected and to measure changes in cognition, memory, comprehension, and personality.

Although patients' needs often seem to take precedence, Lucchesi advises

caregivers to utilize self-care skills. “It’s important that caregivers set aside time to do a hobby, something that brings them joy. They should feel OK about asking for help when they need to find some time to refuel.”

Communicating with others who have encountered similar challenges, via online, telephone, or face-to-face support groups, can help caregivers feel less isolated.