

# Learning from Social Media about the Patient Journey and Adherence



People with Alzheimer’s disease and their care partners are using social media to share their experiences with Alzheimer’s disease and treatment. This unfiltered exchange of information offers access to raw insights that can drive innovative solutions to overcome the challenges of adherence and improve outcomes for patients and healthcare providers (HCPs).

Marketers increasingly recognise the advantages of listening to what patients are saying in social media. “E-patients” have become an important source of unguided input that can help brands better understand the challenges to adherence. It is important, however, to recognise the limitations of social media mining, including bias on the part of overly enthusiastic commenters, or the highly emotional or irrelevant comments of ranters and ravers. To help avoid these limitations, traditional market research techniques still have a role in ensuring that a representative sample is obtained.

This article examines the importance of social media as

a source of insights about patient behaviour that may not be captured elsewhere. These findings were presented at theExLDigital Pharma East conference in October 2010.

## Using Social Media to Understand and Plot the Patient Treatment Journey

Given the volume and diversity of social media conversations, marketers need a blueprint to organise and distill key findings and implications. HealthEd’s health educator and strategy team analysed 2000 comments from 20 web portals in our search for common and actionable insights related to adherence in the Alzheimer’s disease patient journey. We then organised those comments by theme and partnered with our creative team to develop a visual representation of the Alzheimer’s journey. The resulting illustration depicts key barriers, drivers, and educational opportunities — and includes an unexpected barrier in the journey.

## Visualising the Alzheimer’s Patient Journey



### Social Media Mining Confirms Barriers in the Alzheimer's Patient Journey

Our social media mining confirmed the complexity of adherence challenges for people with Alzheimer's. The resulting insights confirmed that patients and care partners:

- May not communicate effectively with their HCPs because of the daily challenges of living with Alzheimer's, and a perceived low efficacy of treatment
- May not understand treatment decisions, what to expect with treatment, or the importance of communicating effectively with the HCP prior to stopping treatment
- Struggle to coordinate multiple care needs, such as driving, home care, and legal and financial issues
- Often seem overwhelmed by having to manage care and treatment decisions
- Do not seem to know what to expect with treatment benefits and side-effects (and when to expect them) and what they should do about side-effects

The journey illustration helps summarise the insights that we gleaned. The journey also emphasises the complexity of the decision-making that care partners and people with Alzheimer's face early in the disease. Treatment is just one of many critical decisions they must confront. A journey illustration helps reinforce the importance of developing adherence programmes focused on more than taking medications (such as reminder programmes). Effective adherence programmes must also address the other factors in a person's life that can influence adherence.

### An Additional and Unexpected Barrier: Mistaking Symptoms for Side-Effects

While analysing our social media verbatims, we noted that treatment may be stopped because of an Alzheimer's symptom rather than a treatment side-effect. We hypothesise that patients and care partners failed to distinguish between symptoms and side-effects, which can be similar or even identical. Our theory is supported by the following comments:

"They did add another Alzheimer's medicine, but she was not well on it, so I took her off after one day."

"He was put on Brand Y last year and improved, but now he started complaining he was tired and didn't sleep last night."

"They put her on Brand X, and she is having delusions and trouble talking."

"She has been on Brand X for five years but started with aggression, so we stopped it."

If people with Alzheimer's stop treatment because they mistake a disease symptom for a treatment side-effect, a significant gap exists in current patient education programmes and materials — a gap that might not have been revealed without social media research.

### Using Social Media Insights to Build Innovative Solutions

After we find an unexpected barrier to adherence, our next step is to develop innovative solutions to help patients, care partners and HCPs overcome that barrier. The goal is to fill the educational need related to adherence and drive positive treatment outcomes through tactics and strategies that:

- Speak with appropriate language and tone that align with

social media conversations

- Help patients and care partners coordinate care after diagnosis and throughout treatment
- Support effective patient-HCP dialogue throughout treatment to support informed treatment decisions

### Conclusion

Educational content derived from social media insights promotes effective dialogue between patients, care partners, and the healthcare team. In turn, this may increase awareness and understanding of barriers for patients and care partners, and help them work with their healthcare team to make informed treatment decisions. Our analysis demonstrates the value of online listening and its potential for improving treatment outcomes. Online communities are an inexpensive source of untapped patient and care partner insights in discussions driven by patients and care partners themselves, versus an outside source. HealthEd found that this unstructured space can uncover unique barriers that can drive potential innovation and add another layer to existing findings from structured research. And the insights are available for analysis immediately.

The benefit of this social media lens can be significant when marketers try to understand the needs of patients and care partners living with complex disease states such as Alzheimer's. In a way, social media conversations are like gems lying just below the surface, waiting for marketers who recognise in educational gaps the opportunity for improving outcomes. Once those gaps are identified, strategic solutions can be crafted to engage patients and care partners hoping to connect with others to find answers to their problems. Our findings uncovered interesting opportunities and underscored our belief that online listening, when done well, can help produce tactics that can in turn improve outcomes for patients, care partners, healthcare providers, and marketers.

To learn more about how social media impacts the patient experience, visit [www.healthed.com/social-media-and-the-patient-journey](http://www.healthed.com/social-media-and-the-patient-journey).

*Note: This analysis was based on raw conversations in the public domain of social media in which all personal identifiable information was stripped. HealthEd has in place standard operating procedures to protect and respect the privacy of patients.*



Chris Kelly, MEd, MA, is director of health education at HealthEd, where he leads the development of a wide variety of patient education programs. He has also worked as a special care manager and counselor for people with Alzheimer's disease. Email: [c.kelly@thehealthgroup.com](mailto:c.kelly@thehealthgroup.com)