



Revolutionizing Dementia Caregiving with Data-Driven Technology:

Enhancing Quality of Care for Individuals with Dementia in Senior Living

JULY 2024

Ella[®]
Elevate Caregiving

Improving the Dementia Caregiving Experience

The challenge on how to best support people living with dementia and their families demands urgent attention. Dementia profoundly affects not only those diagnosed but also their families, caregivers, and the entire healthcare ecosystem. Yet, often, the specific needs of these individuals and their caregivers go unaddressed, leading to significant mental, emotional, physical, and financial burden.

Today, in the United States, millions of families are providing informal (unpaid) care for loved ones with dementia, and this number continues to grow as our population ages. Due to the challenges in the healthcare industry, many caregivers do not receive the guidance or support needed to manage the complexity of this disease and challenging behavioral reactions associated with dementia. This lack of support not only affects the well-being of the caregivers but also has serious implications for the quality of care for the persons living with dementia.

I co-founded our company on the belief that technology can transform caregiving, especially for those caring for people living with dementia. Our innovative mobile app aims to empower caregivers with practical, evidence-based strategies to manage behavioral challenges and improve the quality of life for both the caregiver and the care recipient.

We are proud to report this early data from senior living communities where our app, known as Ella at the time and now rebranded to elbi, was implemented. Authored by Juliet Holt Klinger, MA, this paper highlights our promising value-based results, with significant reductions in challenging behavioral reactions and psychotropic medication usage. We also provide individual case studies.

The insights in this paper not only highlight the effectiveness of our approach but also underscore the importance of providing accessible, culturally competent, and timely support to all caregivers, regardless of their location or background. Our goal with this report is to spark a broader conversation about how we can better support dementia caregivers and, in turn, improve outcomes for those living with dementia.

Together, we can ensure that caregivers are seen, heard, and supported in ways that genuinely make a difference.

Sincerely,

Linda Buscemi, PhD, LPC

Acknowledgements: Report authored by Juliet Holt Klinger, MA

Executive Summary

This paper will detail the use of Ella®, a tech-enabled digital platform, and its impact on dementia caregiving in senior living settings. Ella was introduced into the senior living/long-term care market in 2021.

In this paper, we will outline how the Ella mobile application has assisted direct care workers and clinical staff in implementing highly effective non-pharmacological, person-centered approaches to resolve common but serious dementia-related behavioral challenges and to drive down the use of psychotropic medications.

The results of a specific pilot test of the Ella technology in assisted living licensed memory care settings will be presented as a detailed case study.



The Challenge

Over six million Americans are currently living with dementia, a number that is increasing at a rate of 22% annually. The Alzheimer’s Association predicts that by the year 2050, the number of people aged 65 and older with Alzheimer’s could reach 12.7 million, barring the development of medical breakthroughs to prevent or cure Alzheimer’s disease¹.

As a result, the demand for long-term services and supports (LTSS) is expected to grow sharply over the next decade. If current trends continue, the number of nursing home residents alone could double by 2030.²

This “elder bloom” could leave the nation unprepared regarding a sufficient workforce. According to PHI, one of the nation’s leading authorities on the direct care workforce, “... between 2021 and 2031, the direct care workforce is projected to add more than 1 million new jobs, representing the largest growth of any job sector in the country.

During the same timeframe, nearly 9.3 million total direct care jobs will need to be filled ... ever-greater demand for LTSS—along with the sustained impact of COVID-19 on this sector, slow labor force growth, and a tight labor market overall—is placing intense pressure on direct care workforce employment.”³

The combination of the growing population of persons living with dementia and fewer available caregivers is creating a perfect storm. It is common for people living with Alzheimer’s and other dementias to experience psychiatric and psychological symptoms that cause behavioral

reactions—some of which can pose high risks in senior living and long-term care settings.

Behaviors such as exit seeking, physical altercations with other residents, and unwanted sexual expressions towards other residents are the cause of tragic outcomes for residents, their families, and providers.



The Alzheimer’s Association predicts that by the year 2050, the number of people aged 65 and older with Alzheimer’s could reach 12.7 million.



There is a pervasive misconception that the remedy for these behavioral disturbances lies solely in medical treatment.

Physical resistance to care, late-day agitation, and disinhibition are widespread reactions occurring in nearly 90% of all cases of dementia by some estimates.⁴

A recent nationwide study by Gerlach, Martindale, Bynum, and Davis (2023) showed that of the approximately 1.4 million Emergency Department (ED) visits that are made by patients with Alzheimer’s disease and other forms of dementia each year, behavioral disturbances (e.g., day-night reversal, mood fluctuations, etc.) were listed as a primary reason.

Gerlach et al. (2023), further postulate that the high rates of ED visits for behavioral disturbances reflect the primary caregiver’s difficulty in managing behavioral disturbances.⁵ There is a pervasive misconception that the remedy for these behavioral disturbances lies solely in medical treatment.

The use of sedating medications to decrease these so-called challenging dementia-related behaviors has long been recognized as a poorly informed practice. Yet, it remains a culture of care that is resistant to change. In 1987, the Nursing Home Reform Act (OBRA-87) sought to reduce both the use of physical restraints and antipsychotic use, often referred to as “chemical restraints” due to their deleterious sedating effects.

While antipsychotic use did decline following the enactment of OBRA-87, Crystal et al. (2020), note that usage increased in the late 1990s and 2000s, with the introduction of second-generation antipsychotics, perceived as safer alternatives to first-generation ones.⁶ Usage skyrocketed again with current estimates indicating that 20-30% of all nursing home residents are prescribed these medications.

Although not federally regulated or reported, the numbers in assisted living/memory care centers are estimated to be even higher.⁷

In 2005, the Food and Drug Administration (FDA) issued a Boxed Warning for all atypical antipsychotics based on a systematic meta-analysis that revealed a 70% increased risk of death among elderly patients with dementia receiving antipsychotic treatment.

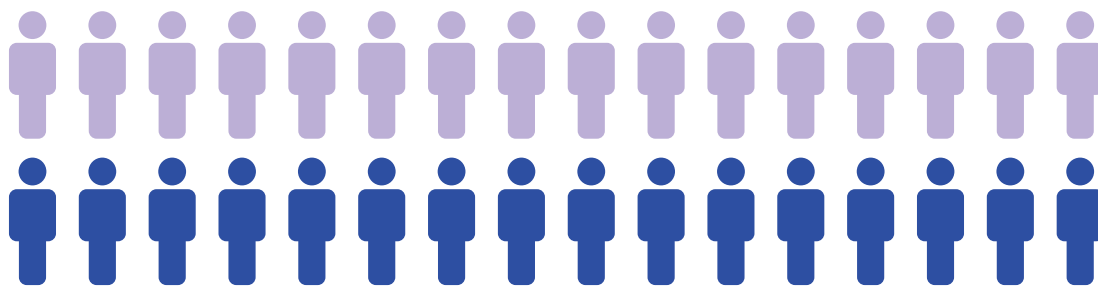
In 2012, Steinberg et al. summarized that, “... meta-analyses of clinical trials have consistently demonstrated a 1.5–1.7 times increased risk of mortality with their use in dementia. Like the atypical antipsychotics, a similar black box warning applies to conventional antipsychotics.

Atypical antipsychotics are also linked to a two- to threefold higher risk of cerebrovascular events (CVAE) (absolute risk of approximately 1%)” (Steinberg, 2012).⁸ Simply put, antipsychotic use in this population increases the risk for death, cerebrovascular adverse events (CVAEs), Parkinsonism, sedation, gait disturbance, cognitive decline and pneumonia (Tampi et al., 2016).⁹

Someone experiencing behavioral reactions is one of the most significant stress factors for professional/paid and family/unpaid caregivers alike.

Dementia-related behavioral symptoms are the most predictive reason for professional caregiver turnover and burnout because they are unpredictable, disruptive, and challenging to manage.

Amongst the most alarming findings, a 2015 study involving nearly 100,000 older adults



(over half with dementia) **who were prescribed an atypical antipsychotic within a 90-day window were 52% more likely to experience a severe fall and 50% more likely to sustain a nonvertebral osteoporotic fracture,** compared to a control group.¹⁰

Today, Alzheimer’s and dementia patients are twice as likely to receive antipsychotic agents as treatment for these symptoms (Gerlach et al., 2023). The necessary change in the culture around treating these symptoms has been difficult to sustain for many reasons. Chief among them is the significant level of stress these behavioral reactions cause for professional/paid and family/unpaid caregivers alike. Dementia-related behavioral symptoms are the most predictive reason for professional caregiver turnover and burnout because they are unpredictable, disruptive, and challenging to manage (Cheng, 2017).¹¹

These factors, amongst others, are exacerbating the professional dementia care workforce crisis. The Washington Post reported that by 2026, an extra 120,000 caregivers will be needed.¹²

In 2017, Weiss et al. identified the need for improvements in care coordination, care management, and the integration of technology to enhance the quality of care for persons living with dementia and support their caregivers. Weiss further suggested that geriatric specialists are needed for their clinical expertise, but due to extra years of training required to support dementia caregiving, facilities must come out of pocket to pay those scarce and expensive experts.¹³



Embracing a Safer and More Effective Model of Care

The limited benefits and problems associated with sedating psychotropic medications, coupled with the current workforce crisis and the rapidly growing population of individuals living with dementia, highlight the urgent need for new, more effective care models. The new path forward must include an easy-to-scale way to implement non-pharmacological, person-centered approaches—considered an essential first step when providing care to persons living with dementia in any setting.

In the Alzheimer’s Association’s landmark 2018 Dementia Care Practice Recommendations, authors Scales, Zimmerman, and Miller outline the best practices for addressing behavioral and psychological symptoms of dementia (BPSD).

Based on their review of the evidence, they suggest these five key practice recommendations to advance dementia care¹⁴:

- 1. Identify** characteristics of the social and physical environment that trigger or exacerbate behavioral and psychological symptoms for the person living with dementia.
- 2. Implement** nonpharmacological practices that are person centered, evidence based, and feasible in the care setting.
- 3. Recognize** that the investment required to implement non-pharmacological practices differs across care settings.
- 4. Adhere** to protocols of administration to ensure that practices are used when and as needed and sustained in ongoing care.
- 5. Develop** systems for evaluating the effectiveness of practices and make changes as needed.

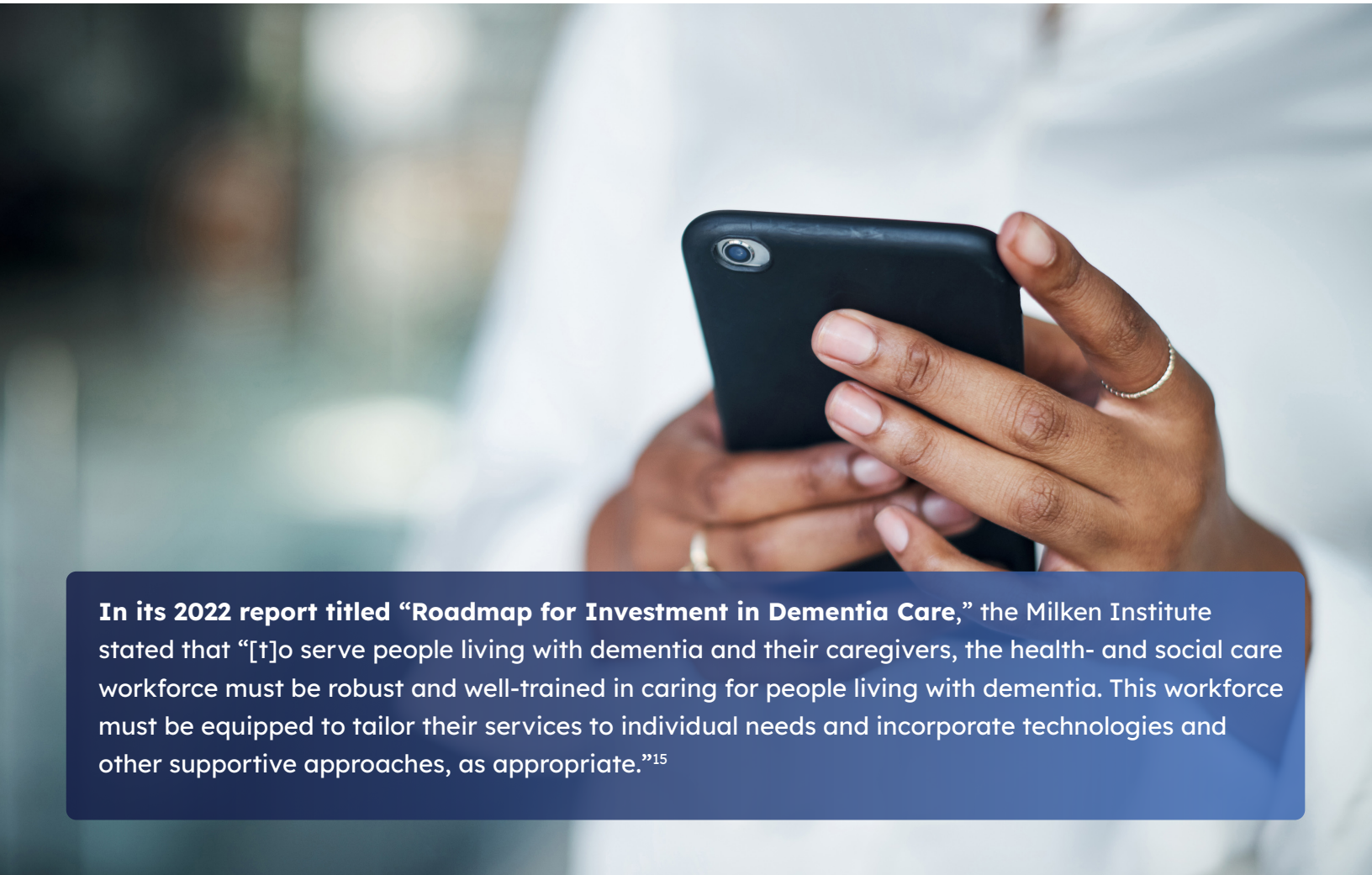
The challenge comes in the dissemination and everyday execution of these practices. How does the senior living/long-term care infrastructure support and meet these requirements when it is already operating from a stressed foundation?

The Technology Imperative

Caring for someone living with dementia is a complex role with a high demand for point-of-care critical thinking skills. Even if a robust workforce were an obtainable reality, accomplishing the amount of training and skill development required to achieve dementia competence while implementing all recommended practices remains an unobtainable goal via traditional methods.

For decades, the senior living industry has held steadfast to a pedagogical approach to staff development that relies predominately on live

classroom or generic dementia content delivered via computer. Despite regulations for dementia training increasing at both federal and state levels, turnover rates have continued to rise, highlighting the inadequacy of this outdated training model in equipping caregivers with the skills needed for complex, person-centered dementia care. There is a *high need* for innovative solutions to assist caregivers in using non-pharmacological approaches to cope with the complicated behavioral symptoms associated with dementia.



In its 2022 report titled “Roadmap for Investment in Dementia Care,” the Milken Institute stated that “[t]o serve people living with dementia and their caregivers, the health- and social care workforce must be robust and well-trained in caring for people living with dementia. This workforce must be equipped to tailor their services to individual needs and incorporate technologies and other supportive approaches, as appropriate.”¹⁵

Leveraging data-driven technology and complex algorithms is ideally suited to support person-centered dementia care. This approach teaches computers to process data in a manner inspired by the human brain, making it an excellent tool to augment the scarce workforce, support stressed family caregivers, and address challenges within the overburdened healthcare ecosystem where the needs of people living with dementia are often overlooked.

The solution: Ella®

In 2019, TapRoot Interventions & Solutions developed Ella®, the first validated behavioral database leveraging complex algorithms to deliver personalized behavioral interventions to dementia caregivers via a smartphone app.

The system collects and analyzes personal information and contextual data to deliver appropriate interventions or approaches directly to caregivers' smartphones or tablets, offering immediate support. TapRoot has demonstrated feasibility with this system by accurately predicting effective behavioral interventions in an initial senior living/nursing home resident population.

Achieving these goals will result in a first-of-its-kind, smartphone-based application that offers tailored interventions to both professional and unpaid (family) caregivers. By preventing and de-escalating adverse behavioral reactions, this innovative solution aims to reduce caregiver

burden and stress and improve the efficiency and quality of life for both individuals living with dementia and their caregivers.

During intake, family members are encouraged to provide important information unique to the care recipient, including the person's background, preferences, routines, and trauma and injury history. This information helps Ella deliver more precise, personalized interventions. This instant provision of personalized approaches relieves the caregiver of the critical thinking burden—knowing when and how to synthesize what is known about the resident into their approaches.

As the caregiver works with the person, they can enter what they are observing, and any time a new behavioral reaction occurs. Each time they log a new reaction, a series of questions unique to that reaction comes up on the app, and from that, the system knows which three to four interventions to suggest. The caregiver tries the approaches and then records the success of that approach with the person.

Ella also provides real-time alerts and immediate notifications to supervisors for three of the highest-risk reactions: physical aggression towards another resident, sexual expressions towards another resident, and exit seeking.

Alerting leadership of these reactions as the caregiver is first noting them enables a timelier response and supports earlier interventions, potentially preventing further or more serious incidents.

The goal is to scale the app for consumer use while continuously refining the system to improve the accuracy of predicting adverse behaviors.

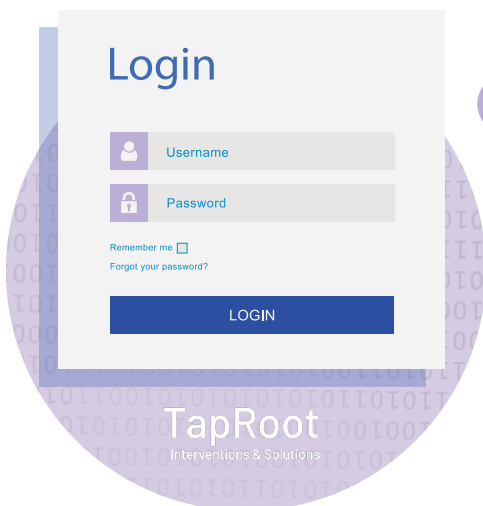
Technical Specifications

The **Ella mobile application** is compatible with any iOS or Android device that meets the minimum requirements set by Apple and Google and the desktop clinical administration, and the dashboard is web-based.



Data Management, security, and quality control on the app are governed by the TapRoot Data Management Retention and Security Policy v1.1 dated September 1, 2023, which adheres to the National Institute of Standards and Technology (NIST) framework.

The Ella platform utilizes a series of APIs to integrate with healthcare systems such as electronic medical/health record software.



The Ella app requires a username and a strong password to access any data in the app. While Protected Health Information (PHI) is not included in the app, TapRoot still maintains high standards of security and confidentiality. Data is encrypted at rest and in transit and is backed up daily to ensure security and confidentiality.

Enabling Greater Communication and Collaboration

In addition to their initial log-in, once per shift, the caregivers log in and give feedback on Ella's interventions and approaches. Ella also allows the caregiver to share information and updates with other members of the care team via a notes function, fostering collaboration and consistency in care. Nurses report that they value these additional insights as they construct care plans and communicate with physicians. Caregivers report a sense of empowerment as their perspective is considered in the care process.



The Arbor Company: A Case Study of Ella Use in Memory Care

The Ella application was implemented in two assisted living communities in their memory care neighborhoods. The pilot study ran from March 1 to June 30, 2024, and the data described here was extracted from the Ella database and the Arbor Company resident records.

Overall Results:

The goals for this pilot were 1) to reduce behavioral reactions in residents living in memory care, 2) to reduce hi-risk behavioral reactions amongst memory care residents, and 3) to reduce the usage of psychotropic medications, particularly PRN medications. On the Ella platform, interventions are considered effective (worked) when caregivers provide feedback indicating that the intervention either “prevented the reaction” or “redirected the reaction” after it was implemented. While several residents in both communities had reductions or elimination of their PRN psychotropic medications, we will highlight the results of four specific resident’s case studies. They highlight how effective interventions led to fewer incidents on reactions and reduced reliance on PRN psychotropics. All residents highlighted had a dementia diagnosis.

The implementation of the digital caregiving tool in each community followed a similar process: an initial period of a few weeks to get all caregivers onboarded and integrating the app into their regular routines. Caregivers were then reminded to provide feedback on all interventions during stand-up and pre-shift meetings. In both settings, caregivers accessed the Ella app through a shared iPad located in a central location of their work area.

Community #1:

Overall intervention effectiveness was at **94.4%** with interventions working **5,759 times out of a total of 6,098**. Interventions for high-risk behavioral reactions (exit seeking, physical aggression towards another resident, or sexual expressions towards another resident) were effective **85.7%** of the time with interventions working **72 times out of a total of 84**.

Community #2:

Overall intervention effectiveness was at **73.4%** with interventions working **466 times out of a total of 638**. Interventions for high-risk behavioral reactions (exit seeking, physical aggression towards another resident, or sexual expressions towards another resident) were effective **73.7%** of the time working **90 times out of a total of 122**.

Individual Case Studies

(derived from both communities)

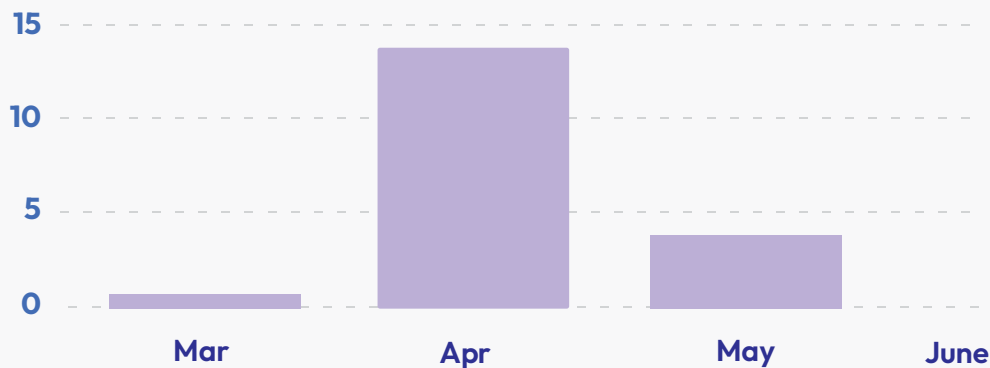


Robert B. (88 yrs.)

Robert B. had one reaction added to Ella by caregivers in March. **Resisting clothes changing**, which was first observed 3/6/2024 and there were 13 instances recorded in April, 4 instances recorded in May and 0 incidents recorded in June. Four interventions were suggested by Ella. Intervention #1 worked 100% of the time, intervention #2 worked 100% of the time, intervention #3 worked 100% of the time, intervention #4 worked 93% of the time.

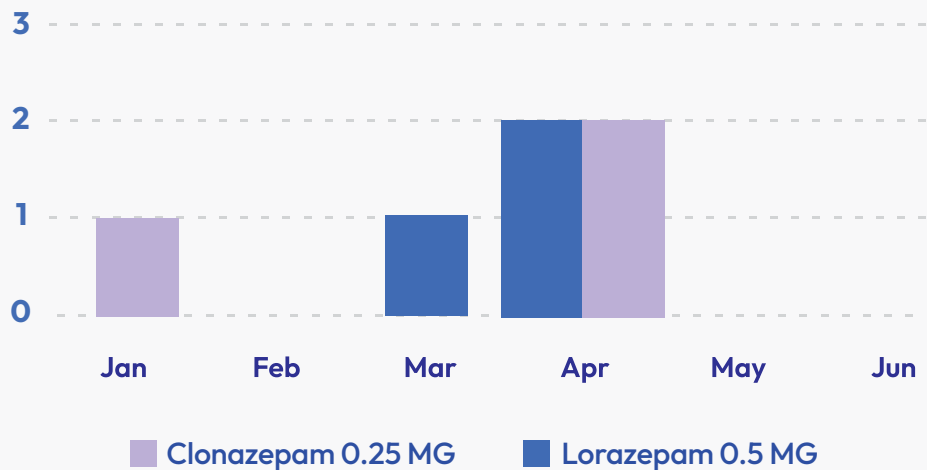
Robert B. Behavioral Reaction Frequency

Resisting Changing Clothes



Robert's PRN doses of both Clonazepam and Lorazepam were reduced after Ella interventions were implemented by caregivers and both PRN **psychotropics were no longer used after April.**

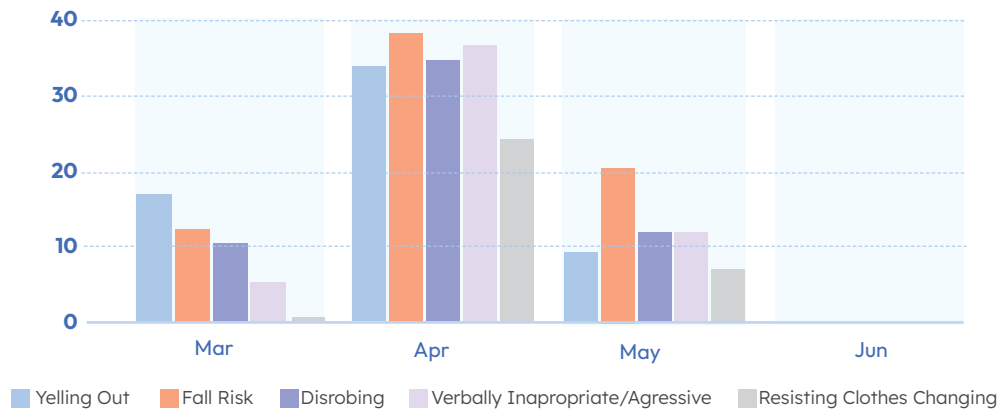
Doses of Clonazepam and Lorazepam



Donald S. (94 yrs.)

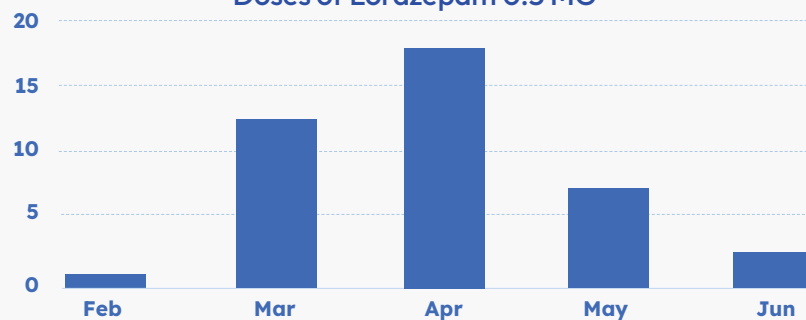
Donald S. had **5 reactions** added to Ella by caregivers (4) in Mar and (1) April. **Disrobing or inappropriate dress** was first observed on 03/27/2024 with 11 instances in Mar, 32 instances in April, 10 instances in May, and 0 in June. Intervention #1 worked 96% of the time, #2 worked 96%, #3 worked 94%, #4 worked 91% of the time. **Fall risk** was first observed on 03/06/24 with 9 instances in Mar, 37 instances in April, and 10 in May. Intervention #1 worked 94%, #2 worked 95% of the time, #4 & #5 worked 0% of the time. **Resisting clothes changing** was first observed on 04/09/2024 with 22 instances in April, 9 instances in May, and none since. Interventions #1 and #2 worked 0% of the time, #3 worked 100% of the time, #4 and #5 worked 0%, #6 worked 98%. **Verbally inappropriate/aggressive** was first observed on 03/27/2024 with 3 instances in March, 35 instances in April, and 10 in May, and none since. Intervention #1 worked 0% of the time, #2 worked 100% of the time, #3 worked 92% of the time, #4 worked 92% of the time, #5 worked 96%, #6 worked 0%. And **yelling out** was first observed on 03/19/2014 with 15 instances in March, 34 instances in April, and 8 instances in May and none since. Intervention #1 worked 0% of the time, #2 worked 90%, #3 worked 88% of the time, #4 worked 93% of the time, #5 worked 89% of the time, #6 worked 0% of the time.

Donald S. Behavioral Reaction Frequency



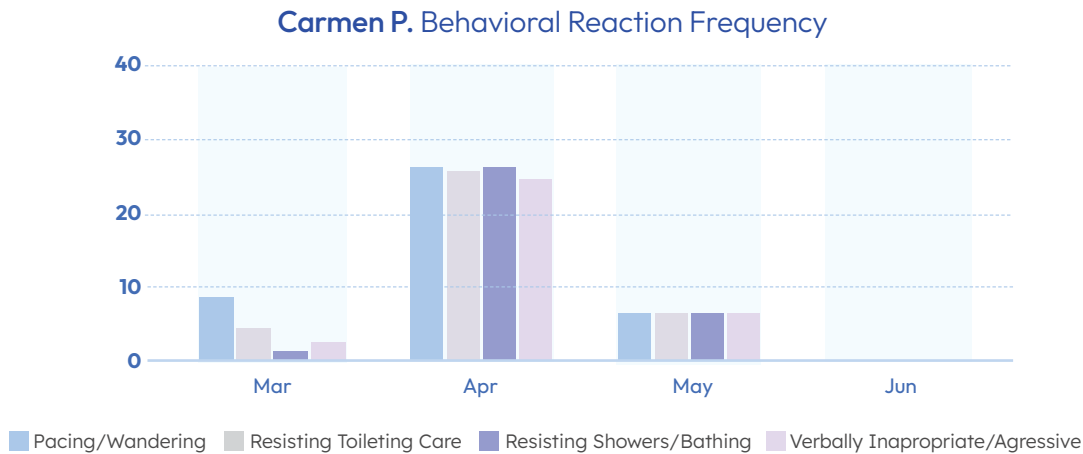
Donald's PRN doses of Lorazepam were reduced after Ella interventions were implemented by caregivers from 18 doses in April to 7 doses in May and 3 doses in June.

Doses of Lorazepam 0.5 MG

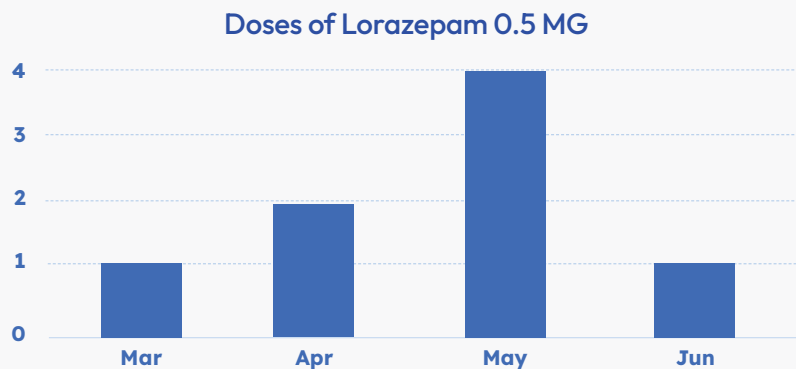


Carmen P. (84 yrs.)

Carmen P. had **4 reactions** added by caregivers in March. **Pacing or wandering** was first observed on 03/6/2024 with 8 instances noted in March, 27 in April, and 8 in May, with 0 in June. Intervention #1 worked 97% of the time, intervention #2 worked 97% of the time, intervention #3 and #4 worked 0% of the time. **Resisting showers/bathing** was first observed on 03/30/24, 25 instances in April, 8 in May, and none noted since. Intervention #1 worked 98% of the time, intervention #2 worked 96% of the time, intervention #3 worked 100% of the time. **Resisting toileting care** was first observed on 03/26/2024 with 8 instances in March, 26 in April, and 8 in May, and none since. Intervention #1 worked 100% of the time, intervention #2 worked 96% of the time, intervention #3 worked 95% of the time, intervention #4 worked 95% of the time. **Verbally inappropriate/aggressive** was first observed on 03/06/2024 with 4 incidents in March, 23 in April, and 8 in May with none since. Intervention #1 worked 98% of the time, intervention #2 worked 96% of the time, intervention #3 and #4 worked 0% of the time and intervention #5 worked 98% of the time.



Carmen’s PRN doses of Lorazepam went from 4 doses in May to 1 dose in June.



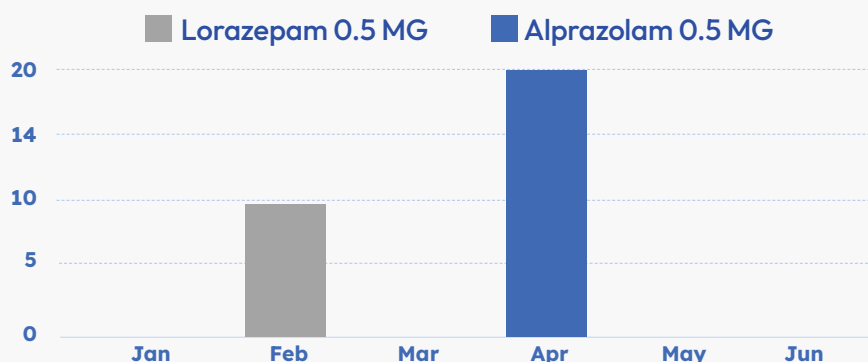
Christine P. (74 yrs.)

Christine P. had **9 reactions** added by caregivers in Mar, Apr, and May. **Disrobing or inappropriate dress** was first observed 03-04-2024 with 2 instances in March. Intervention #1 was effective 100% of the time, #2 30% of the time, and #3 100% of the time. **Easily frustrated** was first observed 04-22-2024 with 3 total incidents in April 1 in May, and 1 in early June. Both interventions worked 100% of the time. **Excessive eating** was first observed 06-07-2024 with 3 incidents noted in June. All 4 interventions worked 100% of the time. **Excessive crying** was first observed on 03-04-2024 with 2 incidents in March, 1 in April, 1 in May and 0 in June. All three interventions worked 100% of the time. **Exit seeking** was first observed on 03-05-2024 with 2 more incidents in June.

Both interventions worked 100% of the time. **Fall risk** was first observed on 06-05-2024 with 2 total incidents in June. All three interventions worked 100% of the time. **Not eating or difficulty dining** was first observed on 05-28-2024, 0 in June. No feedback available on interventions. **Smearing or touching feces** was first observed on 05-21-2024 with 2 more incidents in May, and 2 in June. Four interventions were suggested, intervention #1 worked 100% of the time, #2 worked 50% of the time, #3 worked 50% of the time, and #4 worked 100% of the time. **Yelling out** was first observed on 05-28/2024 with 2 more incidents in June. One intervention selected worked 100% of time.

Christine P. Behavioral Reaction Frequency

	Disrobing	Easily Frustrated	Excessive Eating	Excessive Crying	*Exit Seeking	Fall Risk	Not Eating	Touching Feces	Yelling Out
March	2	0	0	2	1	0	0	0	0
April	0	3	0	1	0	0	0	0	0
May	0	1	0	1	0	0	1	3	1
June	0	1	3	0	2	2	0	2	2



Conclusion

The senior living and long-term care industry will continue to face challenges, especially as the population of residents with high acuity of dementia and behavioral needs continues to grow in the near term. With a limited caregiving workforce, delivering quality, person-centered care requires innovative solutions.

Harnessing the power of data-driven technology and complex algorithms to give caregivers ready answers to care challenges enables a deeper connection to those in their care and is the way forward. By empowering caregivers with data-driven insights and on-demand expertise, the platform helps address behavioral reactions effectively, reducing friction in care interactions and improving overall quality of care. Ella's point-of-care suggestions for proactive and person-centered approaches to common resident reactions not only decrease the need for and reliance on, psychotropic medications but also support senior living residents remaining at a lower level of care for longer.



About TapRoot Interventions & Solutions:

TapRoot Interventions & Solutions created a digital assistant, Ella®, which is a smart guide offering day-to-day personalized solutions for better care interactions and easing caregiver stress.

Ella currently serves dementia caregivers and is agile in supporting caregivers of people living with other conditions. Ella supports population health management principles and enables outcome measures for long-term care operators and payers.

To learn more, please visit our rebranded website <https://www.askelbi.com>.

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