

# Elder Self-Neglect



**Elder self-neglect (ESN)** is a serious public health issue that adversely impacts the health and well-being of millions of older people nationwide. With multiple causes and manifestations, ESN is a complex phenomenon that is difficult for older adults to experience and challenging for professionals to address. It is the concern most frequently reported to Adult Protective Services (APS), with the highest rate of recurrence. Opportunities for resolution are often limited and largely inadequate. ESN may co-occur with and precipitate mistreatment types, including physical, psychological, financial, and sexual elder abuse. As the older population grows, increased exposure to ESN and mistreatment is expected. Meaningful interventions are critical to reduce ESN, mitigate harm, and promote elder wellbeing in later life.<sup>1</sup>

## KEY TAKEAWAYS

- ESN is the most commonly reported concern to APS
- Medical and psychological conditions, isolation, and unavailability of supports can increase the risk of ESN
- ESN is associated with physical decline, depression, poor quality of life, increased hospitalization, and mortality
- The signs are often challenging to detect due to a lack of awareness, insufficient provider training, limited support systems, and insufficient evidence of predictive risk factors
- Promising strategies to address ESN include multidisciplinary collaborations, screening, case management, and access to supportive services



## What is elder self-neglect?

ESN is defined as an older person's "inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks, such as obtaining food, clothing, shelter, and medical care; obtaining goods and services; or managing financial affairs."<sup>2</sup>

ESN has been referred to as a geriatric condition, related to converging cognitive, functional, and/or medical deficits, environmental influences, and inadequate social support.<sup>3</sup> Though more common in older adults, self-neglect is observed across ages, in particular among those with a disease or disability.<sup>4</sup> ESN is often characterized by the inability to maintain socio-cultural accepted standards of self-care, non-adherence to treatment, and maladaptive health behaviors.<sup>5</sup>



## How prevalent is elder self-neglect?

- The estimated prevalence of ESN among community-dwelling older adults ranges from **18.4% to 29.1%**,<sup>6</sup> though ESN is believed to be underrecognized and underreported.<sup>7</sup>
- The number of ESN cases reported to APS has been consistently higher than all other maltreatment types combined (**over 50% experienced ESN in 2022**)<sup>8</sup>
- **Nearly 50%** of APS clients with substantiated reports of ESN have at least one prior report of ESN<sup>9</sup>



## What are the signs of elder self-neglect?

Signs of ESN may be subtle, even unnoticeable at first, and gradually emerge over time into overt and significant health and psychological complications. Older people and those who care for them may not recognize the changes and conditions that signal ESN.<sup>10</sup> For older adults with limited social contact who self-neglect, belated detection can result in deferred diagnosis and increasing harms.

ESN may manifest in multiple and co-occurring ways, including the refusal, failure, or inability of older adults to provide themselves with adequate food, water, clothing, shelter, medication, and safety. Additional signs:

- Living in isolation
- Poor personal hygiene
- Unsanitary living conditions
- Refusal of medical and social interventions
- Untreated medical, psychological, or physical conditions
- Malnutrition and dehydration
- Hoarding<sup>11, 12</sup>



## What are the risk factors associated with elder self-neglect?

The causal factors associated with ESN vary based upon context, sociodemographic factors, health-related conditions, and psychological characteristics, or a combination thereof.<sup>13</sup> Systemic failures, including the unavailability of formal community-based services, have been posited as a contributory or compounding factor.<sup>14</sup> Social determinants of health, the conditions in which people are born, grow, live, and age,<sup>15</sup> can positively or negatively affect one's functional abilities, social connectedness, and the capacity to age in place.<sup>16</sup>

Older adults experiencing ESN often live alone and are socially disconnected from essential services.<sup>17</sup> Lack of instrumental support is believed to be linked to the onset and persistence of ESN, mediating an older person's ability to meet their core needs.<sup>18</sup> Additional research is needed to assess how social determinants impact an older person's susceptibility to ESN or ability to manage their personal, health, and/or financial needs.

The following factors are associated with an increased risk of ESN:

### Sociodemographic Factors



- Limited economic resources<sup>19</sup>
- **Lower income individuals were five times more likely to self-neglect**<sup>20</sup>
- Older age
- 80 years + is associated with increased risk<sup>21</sup>
- Lower education level
- Being male<sup>22</sup>
- Marital status<sup>23</sup>
- Separation or divorce doubled the risk<sup>24</sup>

### Health Conditions

- Cognitive Impairment
- Medical conditions and comorbidities<sup>25</sup>
- Substance use disorder<sup>26</sup>
- Functional deficits
- Poor nutritional status
- Pain<sup>27</sup>
- Disability
- **80%** have one or more disabilities
- **51%** have two or more disabilities<sup>28</sup>

### Psychological and Social Characteristics

- Lower psychosocial function<sup>29</sup>
- Resistance to receiving care from others<sup>30</sup>
- Psychological distress<sup>31</sup>
- Suicidal ideation<sup>32</sup>
- Depression
- **Those who had depression were 2x more likely to experience ESN**<sup>33</sup>
- Fewer social networks and social engagement



### Personal and Provider Perceptions

Understanding the perceptions of older people who self-neglect and the perspectives of the providers who care for them is important to identify the causes of harm and meaningful opportunities for intervention. In a qualitative study examining older adults' views, older respondents attributed their self-neglecting behaviors to physical and mental conditions, lifetime misery, abuse, and loss, and inadequate supportive social networks. Many shared their efforts to maintain control and preserve normalcy in their lives through closely held beliefs, daily practices, and a regular routine. The respondents felt connected to their home, pets, and spirituality. They resisted perceived threats to their identity.<sup>34</sup>

Separately, providers reported that elder isolation and service refusal in cases of ESN inhibited their ability to provide care and raised ethical challenges to the provision of treatment. They struggled with balancing the older person's desire for self-determination with their professional duties to effectively intervene. Study authors suggested the implementation of holistic interventions that address the presenting physical, psychological, and socio-cultural concerns while also integrating the beliefs, capabilities, and strengths of older adults experiencing self-neglect.<sup>35</sup>



## Are ageism and elder self-neglect linked?

Research has shown a connection between ageism and poor health.<sup>36</sup> Individual or internalized ageism may play a significant role in ESN. Internalized ageism, or negative self-perceptions of aging, has been associated with poor mental and physical health.<sup>37</sup> While more research is needed, internalized ageism may place older adults at an increased risk of ESN.



## What is the impact of elder self-neglect?

The manifestations and severity of ESN vary based on the causes, context, and circumstances, but evidence suggests that ESN is associated with significant adversities including physical, psychological, and cognitive impairments, increased health care and service utilization, nutritional deficiency, higher mortality, and poor quality of life.<sup>38</sup> Recent studies have noted increases in nursing home placement, hospice services, hospitalization and readmission.<sup>39</sup> ESN has also been linked with subsequent financial exploitation.<sup>40</sup> **Notably, ESN is associated with a 6x higher increase in mortality.**<sup>41</sup>



***When older adults who self-neglect refuse support from family, friends, and professionals, ESN can be even more difficult to address, exacerbating harm.***

Consequences may include elder abuse, caregiver neglect, and exploitation in later life.<sup>42</sup> Collateral harms include the vicarious stress experienced by family, friends, neighbors, APS caseworkers, and other providers who may experience challenges helping a loved one or client who rejects assistance. The economic impacts of self-neglect are similarly significant and include costs associated with repeated APS investigations, reduced income and productivity of family members caring for a loved one, and decreased employment opportunities for elders experiencing self-neglect.<sup>43</sup>



## What are some challenges to detecting elder self-neglect?

Early identification and intervention are critical to prevent or reduce harm.<sup>44</sup> Researchers have noted several challenges to detecting ESN, including insufficient knowledge and awareness of ESN, limited supportive resources and systems, lack of standardized protocols and training for providers, inadequate evidence of predictive risk factors, and limited reliable, valid, and appropriate ESN assessment tools.<sup>46</sup>



## What is the role of APS, Aging and Disability Networks, and Area Agencies on Aging?

Existing social service programs can offer valuable resources to older adults at risk of or experiencing ESN. APS, Aging and Disability networks, and Area Agencies on Aging (AAA) can provide services, support, and connections to helping resources.<sup>47, 48</sup> As the principal agency responsible for responding to allegations of ESN, APS plays a critical role in supporting vulnerable elders.<sup>49</sup> Intervention is often dependent on the older person's willingness to receive services. Older people with decision-making capacity who experience self-neglect may accept or decline APS intervention. For elders without capacity, APS may intercede, while still respecting a client's autonomy, self-determination, and preferences. Assessing whether ESN is rooted in personal preference or associated with an underlying problem is complicated and requires a nuanced approach, and possibly guidance from a gero-psychologist with expertise in assessing decisional capacity.<sup>50</sup>

Tools to screen for the risk or presence of ESN are available and used by several state APS programs. The Supported Decision-Making (SDM) Assessment and Client Assessment and Risk Evaluation (CARE) have been implemented to improve detection and assessment. Thirty-five state APS programs, however, have reported that they are not currently using a specialized self-neglect assessment tool.<sup>51</sup> A systematic review of ESN screening instruments identified eight tools and found that none demonstrated better methodological quality than any other.<sup>52</sup>



***Given the nature of ESN and unique needs of older clients, some APS programs are shifting to assessment rather than investigation.***

This change would enable caseworkers to focus on service provision, engagement, and cooperative client participation. The most commonly cited service needs reported by APS survey respondents to address ESN rank in descending order from in home assistance, to care/case management, housing and relocation, emergency assistance and material aid, caregiver supports, and public assistance benefits.<sup>53</sup>



## What interventions may be helpful to address ESN?

Addressing ESN requires an understanding of the older adult, their biopsychosocial needs, decisional capacity, their preferred resolutions, and concurrence.

## Strategies



- Multidisciplinary team efforts (e.g., medical professionals, social service agencies, legal service providers, discharge planners, and faith supports), are a preferred approach to screen, assess, and appropriately intervene with older adults exposed to or experiencing ESN
- A combination of medical care, medication, therapies, social services, counselling, and case management may address the constellation of issues associated with ESN and support elder health promotion
- Health care providers should screen older adults with multiple medical comorbidities, depressive symptoms, poor nutrition, and lower levels of cognitive function, who may be at increased risk of ESN
- Health and social service professionals should inquire about the social engagement of older adults at higher risk of ESN
- Strength-based approaches that respect and support the older person's autonomy, resilience, and self-identified coping mechanisms may yield better outcomes
- Improving older adults' resilience and response to the detrimental effects of ageism can help confront ageist attitudes. Two promising approaches focus on increasing self-compassion (being kind rather than critical of ourselves) and self-efficacy (confidence in our own ability to complete a task or achieve a goal)

## Programs



- Direct interventions such as transportation, technology, and social engagement may increase social connection, while indirect interventions such as volunteerism may offer a sense of community, enhance social connection, and meaning making in later life<sup>54</sup>
- A peer program to address loneliness and isolation among low-income older adults showed positive results including sustained improvements in socialization and reduced loneliness and depression<sup>55</sup>
- RISE, a community-based elder abuse and self-neglect intervention in which trained professionals partner with APS to provide referrals and support for older adults experiencing abuse and ESN, has been found successful with clients who had a history of ESN, resulting in a 10-fold reduction in recurrence<sup>56</sup>
- Suggested research topics include strategies to improve health system partnerships with community-based programs,<sup>57</sup> the link between decision making capacity and recurrence of ESN,<sup>58</sup> and the structure, function, and quality of social connection in older adults who experience ESN<sup>59</sup>
- Examining the link between social determinants of health, particularly ageism, and ESN may enhance current understanding about causes and risk factors
- To help overcome challenges in conducting research on ESN, researchers should consider partnering with agencies that investigate ESN, implementing verification strategies to ensure accurate data, and developing strategies for conducting research in a home environment that poses a hazard or challenge<sup>60</sup>

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