

**The Ethics of GPS Tracking of Elderly People with Dementia Living at Home:**  
*A Fused Capability Approach to the Patient's Freedom of Movement, Privacy, and Safety*



Master's Thesis Applied Ethics 2020-2021  
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## Summary

Wandering behaviour is common among people with dementia. For elderly people with dementia living at home, freedom (of movement), privacy, and safety may be at stake because of this. Global Positioning Systems (GPS) tracking is a surveillance technology that can be used to assist dementia patients and their environment in coping with wandering. But GPS tracking raises ethical concerns. Where the current debate could be further developed regarding the patient perspective, this thesis shows how freedom of movement can be put central in our ethical analysis to contribute to this. Using the 'Fused Capability Approach' regarding the patient's freedom of movement, the thesis shows how GPS tracking as a solution to wandering behaviour of elderly people with dementia living at home can be justified to a certain extent, if this happens under a number of interdisciplinarily composed conditions that find a balance between the patient's freedom (of movement), privacy, and safety as part of an ethical triangle, on a case-by-case basis. It is important to deepen this understanding of the patient perspective and explore how it relates to the interests of the other stakeholders with regard to the central theme, in order to get the best out of GPS technology for elderly people with dementia living at home and their environment.

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***“The youth can walk faster but the elder knows the road”<sup>1</sup>***

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<sup>1</sup> African proverb.

## Introduction

In a recent newspaper article about dementia, there was a report about a confused elderly man who drove from Essen in Germany all the way to the Netherlands and landed in a ditch near Utrecht.<sup>2</sup> He had travelled about 200 kilometres from his home towards the Houtenseweg between Utrecht and Houten.<sup>3</sup> He had left on a Sunday morning and the accident took place at 10 pm.<sup>4</sup> The man was missing that day, so his wife raised the alarm.<sup>5</sup> When found, the man appeared confused, and he was believed to have dementia.<sup>6</sup>

Let us suppose that the man indeed had dementia.<sup>7</sup> We can call him Bernhard. What would be the proper response to this situation? What if we had used GPS technology to track Bernhard's movements?<sup>8</sup> Could this kind of incident have been avoided?<sup>9</sup> Would that be desirable, or is it better that people like Bernhard are not tracked and get to decide for themselves what they do? If the latter, such accidents might not be preventable and these people would pose a danger not only to themselves but also to their environment.<sup>10</sup> Although Bernhard ended up in a ditch this time, he could have hit another car. But on the other hand, the use of GPS technology could also jeopardise his freedom and privacy.<sup>11</sup> How do we make the right choices to arrive at an ethically responsible decision about whether to use GPS technology for situations like this?

Perhaps it turns out that in Bernhard's case it would be best to give him GPS technology when he goes out alone. Or maybe he should not even be allowed to drive a car at all (which could possibly also be prevented by the implementation of GPS technology). Consider now the following scenario. This time it is not Bernhard driving 200 kilometres from his home without knowing where he is, but Lewis. Lewis is an 80-year-old former Formula 1 driver, in Stevenage, England. He is an excellent driver. During one of his weekly trips, he does not end up in a ditch, but drives on smoothly. He can still drive very well and knows he is not allowed to go faster than 110 kilometres per hour on British highways,

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<sup>2</sup> Maarten Venderbosch, "Duitser is vermist in eigen land tot hij 200 kilometer verderop bij Utrecht in de sloot rijdt," *Algemeen Dagblad*, March 22, 2021, <https://www.ad.nl/utrecht/duitser-is-vermist-in-eigen-land-tot-hij-200-kilometer-verderop-bij-utrecht-in-de-sloot-rijdt~a9502a12/>.

<sup>3</sup> Ibid.

<sup>4</sup> Ibid.

<sup>5</sup> Ibid.

<sup>6</sup> Ibid.

<sup>7</sup> It was not certain whether the man had dementia, but for this thesis we envision a situation in which the man indeed had dementia.

<sup>8</sup> There are examples of large-scale searches to find missing persons. Perhaps the use of GPS trackers can prevent this. Maaïke Kooistra, "Demeterende Theo (87) op zo'n acht kilometer van huis teruggevonden na urenlange zoektocht," *Algemeen Dagblad*, March 24, 2021, <https://www.ad.nl/utrecht/dementerende-theo-87-op-zon-acht-kilometer-van-huis-teruggevonden-na-urenlange-zoektocht~aac7c0b6/>.

<sup>9</sup> I will elaborate on this in section 1.

<sup>10</sup> Sara Shu, and Benjamin KP Woo, "Use of technology and social media in dementia care: Current and future directions," *World Journal of Psychiatry* 11, no. 4 (2021): 112.

<sup>11</sup> Y. Tony Yang, and Charles G. Kels, "Does the shoe fit? Ethical, legal, and policy considerations of global positioning system shoes for individuals with Alzheimer's disease," *Journal of the American Geriatrics Society* 64, no. 8 (2016): 1708.

but he just does not know very well where he is going; his orientation capacity is diminishing, and he is becoming a bit forgetful. Could the use of GPS tracking technology be justified in this situation? Lewis might be less of a direct threat to himself and his environment than Bernhard. Nevertheless, there is a risk that Lewis will no longer find his way back home. Lewis has the capability to drive a car safely, but is it still justified and responsible for Lewis to roam freely without tracking devices?

Both cases illustrate the complexity of the ethical dilemma involved in the use of GPS technology for elderly people with dementia living at home (EDLH), who tend to wander. You may think it is more justified to implement the technology in Bernhard's case than in Lewis' case, or that the technology should under no circumstances be used in either case. The fact is that it is difficult to get a grip on the situation in practice. EDLH can differ from each other. Everyone goes through different phases of dementia at a different pace and in his or her own way, related to his or her own identity. This makes it difficult, unfeasible, and undesirable to align (the justification of) the policy surrounding the use of GPS technology for this target group.

In this thesis I investigate the ethical issues that arise regarding the implementation of GPS tracking devices, for EDLH who tend to wander. The increasingly aging world population will result in a growing demand for elderly care.<sup>12</sup> The number of people with dementia worldwide is increasing and the pressure on healthcare institutions as well.<sup>13</sup> This in turn increases the risk of incidents with these people.<sup>14</sup> Accidents such as the one in the case study will occur more often. To make healthy aging possible for all elderly people, the number of e-Health implementations, such as monitoring or tracking technologies, is enlarged.<sup>15</sup> The corona crisis has also given a major boost to the implementation of e-Health in healthcare.<sup>16</sup> These factors create a great interest in making the right decisions about whether to use technologies such as GPS tracking in EDLH care.

In what follows, I provide an overview of the key ethical concepts at stake in GPS tracking for EDLH, as well as a critical appraisal of the ethical debate on this topic, which results in an ethical point of view I consider deserving more attention. I assess the extent to which the debate has so far succeeded in creating insight into the patient perspective of EDLH. The method I use for this is a capability approach (CA) that can fill the gaps in the debate regarding the patient perspective.<sup>17</sup>

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<sup>12</sup> Yao Sun, et al., "GPS Tracking in Dementia Caregiving: Social Norm, Perceived Usefulness, and Behavioral Intent to Use Technology," *Proceedings of the 54th Hawaii International Conference on System Sciences*, 2021, 3804.

<sup>13</sup> "Facts and figures," Alzheimer's Association, last modified, 2021, <https://www.alz.org/alzheimers-dementia/facts-figures>.

<sup>14</sup> Ibid.

<sup>15</sup> Ministerie van Volksgezondheid, Welzijn en Sport, "Stand van zaken e-health in 2020," Accessed May 14, 2021, [https://www.rivm.nl/sites/default/files/2020-12/Stand\\_van\\_zaken\\_e-health\\_in\\_2020\\_TG\\_bev.pdf](https://www.rivm.nl/sites/default/files/2020-12/Stand_van_zaken_e-health_in_2020_TG_bev.pdf), 8.

<sup>16</sup> Ibid., 18.

<sup>17</sup> Ingrid Robeyns, and Morten Fibieger Byskov, "The Capability Approach," in *The Stanford Encyclopedia of Philosophy* (Winter 2020 Edition), ed. Edward N. Zalta (ed.), <https://plato.stanford.edu/archives/win2020/entries/capability-approach/> (accessed June 15, 2021), 3.

My research question is: To what extent can the use of GPS tracking as a solution to wandering behaviour of EDLH be ethically justified from the point of view of a capability approach to the freedom (of movement), privacy, and safety that are at stake for the patient? My main thesis is that the use of GPS tracking as a solution to wandering behaviour of EDLH can be ethically justified to a certain extent from the point of view of a Fused Capability Approach to the patient perspective, if this happens under a number of interdisciplinarily composed conditions that find a balance between the patient's freedom (of movement), privacy, and safety as part of the perceived ethical triangle, on a case-by-case basis.<sup>18</sup>

In section 1, I provide necessary background. I explain what wandering behaviour and GPS tracking means<sup>19</sup>, elaborate the practical context of the issue, and introduce the so-called ethical triangle. This will show why we should assess the use of GPS technology on a case-by-case basis. In Section 2, I outline the general debate surrounding GPS tracking for people with dementia and beyond, key ethical values, and two extreme positions between which we must find an intermediate way. Section 3 shows how the authors in the debate recognise the importance of including the patient's perspective and how they they consider consent to be important.<sup>20</sup> I outline two limitations surrounding this emphasis on consent in section 4, after which I argue that a modern understanding of freedom of movement does more justice to the versatility of interests that converge in the patient perspective. In section 5, I argue for the importance of the CA to our understanding of freedom of movement in this context, distinguishing between two possible interpretations of the CA: one focusing on Martha Nussbaum's list of central human functional capabilities<sup>21</sup> and another one I call the 'stage of life capability approach'<sup>22</sup>. In section 6, the two approaches are compared. I will provide a critical appreciation of the stage of life capability approach to the debate but explain why it does not suffice. In section 7, I advocate a Fused Capability Approach, in which the stage of life capability approach is enriched with a place-based capability approach.<sup>23</sup> I will show how this approach can be helpful to find the balance between the two extreme positions. It will be concluded that the central thesis can be adopted, and I outline a number of conditions for the use of this technology in this context. In section 8, three possible counterarguments are anticipated.<sup>24</sup> Section 9 concludes my discussion.

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<sup>18</sup> I will explain the different concepts later. I will be explicitly talking about the *ethics* of GPS tracking of EDLH. The legal perspective falls outside the scope of this research.

<sup>19</sup> Dirk Lukkien, and Sandra Suijkerbuijk, "Keuzehulp GPS-systemen: voor mensen met dementie of een verstandelijke beperking," Vilans, December, 2015, <https://www.vilans.nl/vilans/media/documents/producten/keuzehulp-gps-systeem-voor-mensen-met-dwaalgedrag.pdf>, 2.

<sup>20</sup> Ruth Landau, and Shirli Werner, "Ethical aspects of using GPS for tracking people with dementia: recommendations for practice," *International Psychogeriatrics* 24, no. 3 (2012): 358.

<sup>21</sup> Martha Nussbaum, "Women's capabilities and social justice," *Journal of human development* 1, no. 2 (2000): 219-247. & Manik Gopinath, "Thinking about later life: insights from the capability approach," *Ageing international* 43, no. 2 (2018): 231-235.

<sup>22</sup> Michael Dunn, "Realizing and maintaining capabilities: Late life as a social project," *Hastings Center Report* 48 (2018): S26.

<sup>23</sup> Ingrid Robeyns, "Wellbeing, place and technology," *Wellbeing, Space and Society* 1 (2020): 1.

<sup>24</sup> Tom L. Beauchamp, and James F. Childress, *Principles of Biomedical Ethics*, 7th ed. Oxford: Oxford University Press, 2009, 216-223.

# 1. Background

## 1.1 Introduction to the issue

The world population is aging.<sup>25</sup> Where there was a population of 1 billion people over 60 in 2019, this will increase to 2.1 billion people in 2050.<sup>26</sup> There will also be an increased number of people with dementia.<sup>27</sup> The combination of these two developments means that there will be a growing demand for elderly care, in particular for people with dementia.<sup>28</sup> This entails great costs and it requires a large investment of time in the care for these people.<sup>29</sup> Dementia is also a major cause of death.<sup>30</sup> With a third of the elderly people dying with dementia in America, the urgency of research into how to prevent this is evident.<sup>31</sup>

There are different forms of dementia.<sup>32</sup> The most well-known type is Alzheimer's disease.<sup>33</sup> Within this thesis, no distinction is made between the different types of dementia. Rather, dementia is understood in all its type and practical implications. It is important to understand the variety of how dementia affects people's lives in practice in making appropriate ethical considerations regarding this theme.

## 1.2 Wandering behaviour and dementia

Much has been written about wandering behaviour of people with dementia and it is good to try to understand what exactly happens when people start to wander.<sup>34</sup> People with dementia may tend to wander, which can result in them getting lost.<sup>35</sup> The Alzheimer's Association characterises wandering behavior as follows:

Alzheimer's disease causes people to lose their ability to recognise familiar places and faces. It's common for a person living with dementia to wander or become lost or confused about their location, and it can happen at any stage of the disease. Six in 10 people living with dementia will wander at

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<sup>25</sup> "Ageing," World Health Organization, last modified September 21, 2020, [https://www.who.int/health-topics/ageing#tab=tab\\_1](https://www.who.int/health-topics/ageing#tab=tab_1).

<sup>26</sup> Ibid.

<sup>27</sup> Alzheimer's Association, "Facts and figures."

<sup>28</sup> Ibid.

<sup>29</sup> Sun, et al., "GPS Tracking in Dementia Caregiving," 3804.

<sup>30</sup> Alzheimer's Association, "Facts and figures."

<sup>31</sup> Ibid.

<sup>32</sup> "Dementia," World Health Organization, last modified September 21, 2020, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

<sup>33</sup> Ibid.

<sup>34</sup> Eleanor Bantry White, and Paul Montgomery, "Electronic tracking for people with dementia: an exploratory study of the ethical issues experienced by carers in making decisions about usage," *Dementia* 13, no. 2 (2014): 217.

<sup>35</sup> "Stages of Alzheimer's," Alzheimer's Association, last modified, 2021, <https://www.alz.org/alzheimers-dementia/stages>.



least once; many do so repeatedly.<sup>36</sup>

Wandering behaviour can be life-threatening.<sup>37</sup> It can result in injury, dehydration, and hypothermia.<sup>38</sup> It is therefore considered unsafe.<sup>39</sup> And as we saw in Bernhard's case, it can also endanger the person's environment. In addition to the unsafety of the person him or herself, it is also stressful for the caregiver of the person suffering from dementia.<sup>40</sup> As a result, it is sometimes decided to lock people with dementia who tend to wander in their home or have them admitted to a nursing home.<sup>41</sup> This in turn can have major consequences for the capabilities of these people.

An example of what is being done about the issue of wandering at the moment is Project Lifesaver (founded in 1999 in Virginia, United States).<sup>42</sup> Initiatives like this aim to prevent dangerous situations surrounding people with cognitive disorders who tend to wander.<sup>43</sup> They use locating technologies in combination with search strategies, which have helped them reduce search times by up to 95% compared to searches without this Project Lifesaver method.<sup>44</sup> To visualise how the use of technology can help in contexts of wandering EDLH, it is important to first map out what GPS tracking itself exactly means.

### 1.3 What is GPS tracking?

A lot of research is being conducted into how technological innovation can be used in the care of people with dementia.<sup>45</sup> New technologies and developments in e-Health enable us to monitor the behaviour of EDLH.<sup>46</sup> Think, for example, of motion sensors in a home situation.<sup>47</sup> Such technologies make it possible to keep an eye on people with dementia from a distance, for safety reasons.<sup>48</sup> GPS are a form of "positioning surveillance" and allow us to see where a person is on the Earth.<sup>49</sup> GPS trackers

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<sup>36</sup> "Wandering," Alzheimer's Association, last modified, 2021, <https://www.alz.org/help-support/caregiving/stages-behaviors/wandering>.

<sup>37</sup> "PLI TECH STATEMENT," Project Lifesaver: Bringing Loved Ones Home, last modified, 1999-2019. <https://projectlifesaver.org/locating-technology/pli-tech-statement/>.

<sup>38</sup> White, and Montgomery, "Electronic tracking for people with dementia," 217.

<sup>39</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 358.

<sup>40</sup> White, and Montgomery, "Electronic tracking for people with dementia," 217.

<sup>41</sup> Ibid., 217.

<sup>42</sup> Project Lifesaver, "PLI TECH STATEMENT."

<sup>43</sup> Ibid.

<sup>44</sup> Ibid.

<sup>45</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 358.

<sup>46</sup> Shane A. Lowe, and Gearóid ÓLaighin, "Monitoring human health behaviour in one's living environment: a technological review," *Medical engineering & physics* 36, no. 2 (2014): 147.

<sup>47</sup> Ibid., 147.

<sup>48</sup> Niemeijer, et al., "The ideal application of surveillance technology in residential care for people with dementia,"

<sup>49</sup> Karen Eltis, "Predicating dignity on autonomy—the need for further inquiry into the ethics of tagging and tracking dementia patients with GPS technology," *Elder LJ* 13 (2005): 397.



can also be used to assist in the care EDLH.<sup>50</sup> For example, they can be used to track down a wandering demented person and bring him home safely.<sup>51</sup>

GPS trackers are available in various forms, e.g., a belt, necklace, phone, or watch (see figure 1,<sup>52</sup> 2,<sup>53</sup> and 3<sup>54</sup>).<sup>55</sup> But there are also more striking types such as the GPS shoe<sup>56</sup> or even the GPS chip implant<sup>57</sup>. Each system and brand has its own associated functions.



Figure 1

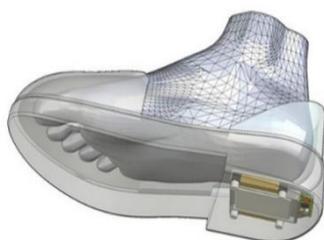


Figure 2



Figure 3

For example, in a comparative study by the Dutch organisation Vilans, the following functions are distinguished: sending a message after pressing an alarm button, establishing a speaking-, and listening connection after pressing an alarm button, traceability via a mobile app, portable device or online portal, a 'safe zone' function, one or more contacts, a link with the emergency centre, the possibility to view previous locations (history) and automatic location updates.<sup>58</sup> In this thesis, the focus is not on the appearance of the product. In principle, I will not distinguish between GPS watches, shoes, or necklaces.<sup>59</sup> It is, however, relevant to distinguish among functions. I will focus on a GPS tracker system that remembers locations, features a 'safe zone' function, can send messages after pressing an alarm button, can establish a speaking-, and listening connection after pressing an alarm button, and has a link with the emergency centre. The reason I choose this focus is because such systems might have helped to prevent Bernhard's incident.

If Bernhard had been given a GPS tracker and agreed to set up a safe zone in consultation with his wife and son, he might not have ended up on the highway in the first place. As a safe zone, a certain area around

<sup>50</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 358.

<sup>51</sup> Yang, and Kels, "Does the shoe fit?" 1708.

<sup>52</sup> "Hét alarm horloge voor senioren," Spotter, accessed June 19, 2020, <https://www.spottergps.com/gps-horloge/senioren-alarm/>.

<sup>53</sup> Darren Quick, "Comfort shoes with embedded GPS to keep track of Alzheimer's patients," *New Atlas*, October 27, 2011, <https://newatlas.com/gps-shoe/20291/>.

<sup>54</sup> "Spotter® GPS tracker voor alles wat je lief is," Spotter, accessed June 19, 2020, <https://www.spottergps.com/>.

<sup>55</sup> Lukkien, and Suijkerbuijk, "Keuzehulp GPS-systemen," 13-24.

<sup>56</sup> Yang, and Kels, "Does the shoe fit?" 1708.

<sup>57</sup> White, and Montgomery, "Electronic tracking for people with dementia," 223-224.

<sup>58</sup> Lukkien, and Suijkerbuijk, "Keuzehulp GPS-systemen," 13-24.

<sup>59</sup> Although the appearance of the GPS technology can influence the desirability of the use of the technology for EDLH, partly because of ethical problems surrounding stigmatisation (more about this in section 1.4), this is not the ethical problem I will focus on in this thesis.





Figure 4

Bernhard's house in Essen could have been demarcated (see figure 4<sup>60</sup>).<sup>61</sup> If he crosses the borders of this area on a Sunday morning, his son and wife are notified.<sup>62</sup> Perhaps it would have been possible to prevent Bernhard from driving onto the highway towards the Netherlands. Maybe Bernhard would have pressed the alarm button because he did not know how to get home, which would have enabled his wife or son to reassure him.<sup>63</sup> They could have checked his location and even seen the path he had taken to get there.<sup>64</sup> This could help explain to someone like Bernhard where he is and how to get home.<sup>65</sup> Because Bernhard was not walking but driving a car, making him a direct danger to himself and his environment, a link with the emergency centre could help as well. So, a GPS tracker with the mentioned functions could possibly prevent many dangerous situations.

#### 1.4 The practical context

Several practical implications are associated with the possible use of GPS tracking for EDLH. GPS tracking systems can fail to function properly.<sup>66</sup> If a GPS tracker sends erroneous information, who is responsible?<sup>67</sup> While I will not be focusing on this in my thesis, it is important to keep in mind that what technology promises to do will not always work naturally.<sup>68</sup> It is therefore important to only implement GPS technology for the right reasons.

In addition, carrying a large GPS device can have a stigmatising effect.<sup>69</sup> Tracking people with dementia via a GPS tracker is considered by some as undermining the dignity of these people.<sup>70</sup> On the other hand, there are also claims that GPS tracking is doing just the opposite, because it prevents even worse, more stigmatising events from happening.<sup>71</sup>

<sup>60</sup> "Veilig GPS kinderhorloge, waar moet u op letten?" Spotter, accessed May 20, 2020, <https://www.spottergps.com/kennisbank/kind/veilig-gps-kinderhorloge/>.

<sup>61</sup> Dirk Lukkien, Sandra Suijkerbuijk, and Johan van der Leeuw, *Op zoek naar een bruikbaar GPS-systeem voor mensen met dementie of een verstandelijke beperking: Overzicht huidige GPS-lokalisatiesystemen en resultaten bruikbaarheidsonderzoek* (Utrecht: Vilans, December 2015), <https://www.vilans.nl/docs/vilans/publicaties/onderzoeksrapport-gps-lokalisatietechnologie.pdf>, 9.

<sup>62</sup> Ibid., 9.

<sup>63</sup> Ibid., 8-9.

<sup>64</sup> Lukkien, and Suijkerbuijk, "Keuzehulp GPS-systemen," 13-24.

<sup>65</sup> Lukkien, Suijkerbuijk, and Van der Leeuw, *Op zoek naar een bruikbaar GPS-systeem voor mensen met dementie of een verstandelijke beperking*, 8-9.

<sup>66</sup> Katina Michael, Andrew McNamee, and Michael G. Michael, "The emerging ethics of humancentric GPS tracking and monitoring," (2006), 6.

<sup>67</sup> Ibid., 6.

<sup>68</sup> Lukkien, and Suijkerbuijk, "Keuzehulp GPS-systemen," 13-24.

<sup>69</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 364.

<sup>70</sup> Yang, and Kels, "Does the shoe fit?" 1711

<sup>71</sup> White, and Montgomery, "Electronic tracking for people with dementia," 221



There is also the financial aspect. The costs for GPS tracking devices range from 70 - 700 euros.<sup>72</sup> This is not by default reimbursed by insurance companies.<sup>73</sup> This can raise concerns about the accessibility and affordability of GPS devices, which could result in inequality issues. With the commercial availability and use of trackers we also risk that EDLH will be seen as customers rather than patients, which could result in companies collecting data from these people and also using targeted advertisements. We need to take this into account in our considerations regarding the justification of using these GPS trackers for EDLH, although this will not be the core focus here.

## 1.5 An ethical triangle

In this subsection, I discuss the three core ethical values that emerge at first sight when discussing the possible use of GPS tracking for EDLH: an 'ethical triangle' (see figure 5).

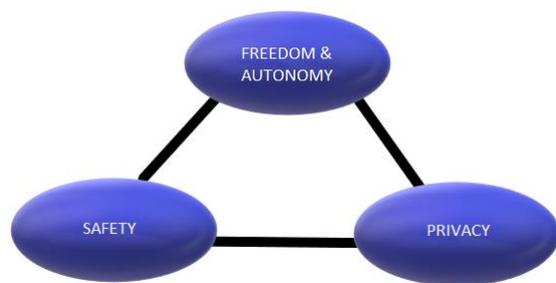


Figure 5

*Safety* – Bernhard was a danger to himself and his environment. Things could have turned out much worse. There seems to be a conflict between patient and public welfare on the one hand, and Bernhard's autonomy on the other.<sup>74</sup> He could have driven into oncoming traffic, driven way too fast or slowly, or caused accidents involving other people. Without the use of GPS technology, we run a greater risk of people like Bernhard causing accidents than with the use of a GPS tracker. Someone could be taken off the road (I am not discussing the desirability of this) or prevented from driving at all, by measuring when he leaves his house and walks towards the parking lot. GPS tracking could therefore help to guarantee the safety of EDLH.<sup>75</sup> On the other hand, is safety always a good starting point for considering whether to use GPS technology in a specific case? Recall the case of Lewis. Lewis can drive safely; except he occasionally forgets where he is going. But he is no danger to other drivers. Should we still give him a tracker and get him off the highway if possible? Taking safety as a starting point becomes a lot more complex here. Now it is not about direct safety considerations on the road, but also about less direct safety considerations that arise because of

<sup>72</sup> Lukkien, and Suijkerbuijk, "Keuzehulp GPS-systemen," 13-24.

<sup>73</sup> Alzheimer Nederland. *Keuzewijzer 2021: Welke zorg en ondersteuning bij dementie wordt vergoed in 2021?* December 2020, [https://www.alzheimer-nederland.nl/sites/default/files/directupload/keuzewijzer-2021.pdf?utm\\_source=content&utm\\_medium=dementienl&\\_ga=2.96042074.797821925.1621337393-693688343.1616850579](https://www.alzheimer-nederland.nl/sites/default/files/directupload/keuzewijzer-2021.pdf?utm_source=content&utm_medium=dementienl&_ga=2.96042074.797821925.1621337393-693688343.1616850579).

<sup>74</sup> Samuel Knapp, and Leon VandeCreek, "Ethical and Patient Management Issues With Older, Impaired Drivers," *Professional Psychology: Research and Practice* 36, no. 2 (2005): 197.

<sup>75</sup> Ruth Landau et al., "Who should make the decision on the use of GPS for people with dementia?," *Aging & mental health* 15, no. 1 (2011): 78.



getting lost and not knowing the way back home.<sup>76</sup> We must therefore also look at the other ethical values involved.

*Freedom* – Despite his dementia, Bernard has the right to freedom of movement, like any other person.<sup>77</sup> Bernhard also has the right to drive cross-country on a Sunday morning.<sup>78</sup> Article 13 of the Universal Declaration of Human Rights (UDHR) defines this right in the following way: “1. Everyone has the right to freedom of movement and residence within the borders of each state. 2. Everyone has the right to leave any country, including his own, and to return to his country.”<sup>79</sup> If we choose not to give Bernhard a GPS tracker, his freedom will not be *directly* affected. Should we choose to give him a GPS tracker, the influence of this on Bernhard's freedom could be understood in two ways. We could see the tracker system as a restriction of his freedom because he can no longer go anywhere undisturbed without someone watching him.<sup>80</sup> Setting a ‘safe zone’ for Bernhard would in practice make his world significantly smaller, which limits his freedom of movement. But on the other hand, the tracker can slow down Bernhard's reduction of freedom, because without the GPS he might have to be transferred to a nursing home.<sup>81</sup> In a slightly less direct way, this restricts Bernhard's freedom of movement all the more and he loses the freedom to live in his own neighbourhood and perhaps even to go outside at all.

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<sup>76</sup> Ibid., 78.

<sup>77</sup> “Universal Declaration of Human Rights,” United Nations, accessed May 14, 2021.

<https://www.un.org/en/about-us/universal-declaration-of-human-rights>.

<sup>78</sup> Ibid.

<sup>79</sup> Ibid.

<sup>80</sup> Landau, and Werner, “Ethical aspects of using GPS for tracking people with dementia,” 359.

<sup>81</sup> Ibid., 359.



*Privacy* – When we talk about privacy in considering the use of a GPS tracker, we must take two things into account. If we decide not to use a GPS tracker, the privacy of EDLH, such as Bernhard,

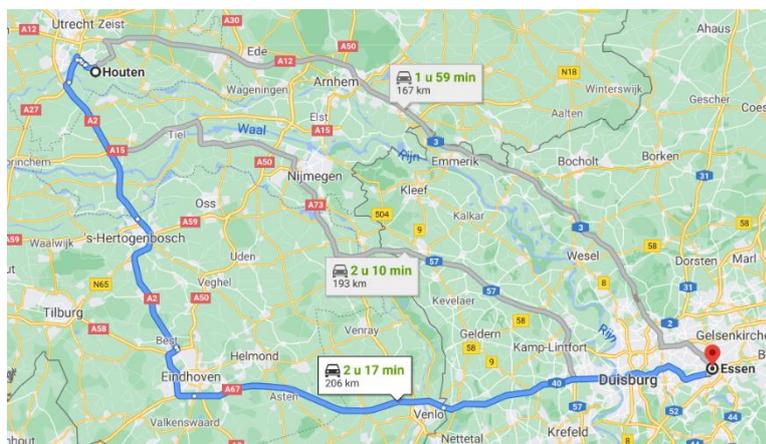


Figure 6

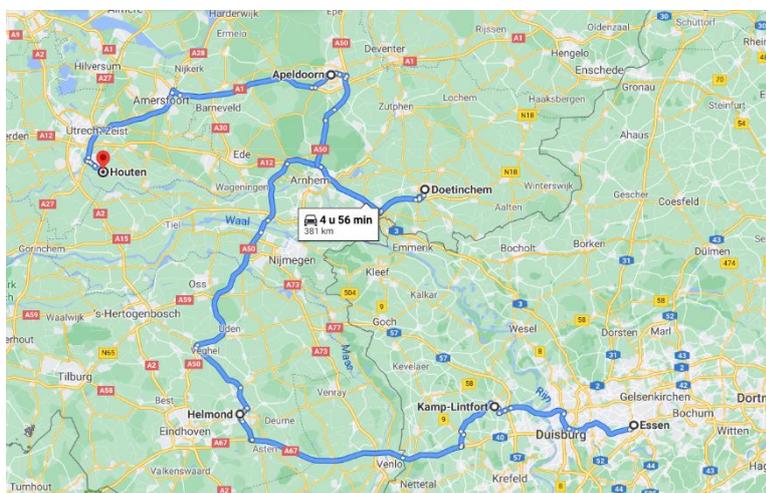


Figure 7

can be limited. On the one hand, this can happen because his children have to come by more often to check how things are going. It may also be decided that Bernhard needs to go to a nursing home, taking away almost his complete privacy.<sup>82</sup> On the other hand, the use of GPS technology would also cause privacy issues.<sup>83</sup> Imagine that your loved ones can see exactly where you are going all day.<sup>84</sup> Bernhard has been driving from morning to 10 pm to drive 200 kilometres. That takes 1 hour and 59 minutes via the fastest route (see figure 6<sup>85</sup>). Even if you would take a detour from Essen to Kamp-Lintfort, to Helmond, to Doetinchem and via Apeldoorn to Houten (which is almost twice as far), it will take you no more than 5 hours (see figure 7<sup>86</sup>). Chances are that Bernhard has stopped somewhere in the meantime. Although GPS tracking of someone with dementia may seem harmless at first sight, it can reveal sensitive information that needs to be handled appropriately.<sup>87</sup> What if Bernhard's GPS tracking yields information the technology was not initially meant for? What if his wife or son discovered that he has gone to a casino or a Dutch coffee shop? What if they found out that Bernhard stood still for two hours in front of his ex-wife's house? The use of GPS tracking technology can compromise the privacy of the tracked person. This conflicts

<sup>82</sup> Ibid., 359.

<sup>83</sup> Ibid., 359.

<sup>84</sup> Another concern is that the use of GPS tracking may result in the fact that people tend to visit their parents less often to check on how they are doing, because they can track them remotely.

<sup>85</sup> Route, Google Maps, accessed April 9, 2021, <https://www.google.nl/maps/dir/Houten/Essen,+Duitsland/>.

<sup>86</sup> Route, Google Maps, accessed April 9, 2021, <https://www.google.nl/maps/dir/Essen,+Duitsland/Kamp-Lintfort,+Duitsland/Helmond/Doetinchem/Apeldoorn/Houten/>.

<sup>87</sup> Eltis, "Predicating dignity on autonomy-the need for further inquiry into the ethics of tagging and tracking dementia patients with GPS technology," 391.



with article 12 of the UDHR: “No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation [...]”<sup>88</sup> Yet, you could also argue that this could be breached in certain circumstances, for example when it comes to certain duties of care.<sup>89</sup> Privacy, freedom and safety can conflict strongly in the case of GPS tracking of EDLH.<sup>90</sup>

## 1.6 The need for ethical consideration on a case-by-case basis

Each of the three themes outlined above can be balanced in two ways, making it a complex issue as to whether it is justifiable to implement GPS tracking technology in the lives of EDLH. People with dementia can also differ greatly from one individual to the other, just as there is also a clear difference between the capabilities of Bernhard and Lewis. We really cannot do anything else than consider whether GPS tracking technology should be used on a case-by-case basis.

## 2. The debate

### 2.1 The different stakeholders and disciplinary perspectives

Before we can make statements about how to best decide on a case-by-case basis whether EDLH should be tracked by means of a GPS tracker, we first must map out the debate on this.<sup>91</sup> Much has been written about GPS tracking of human beings or pets.<sup>92</sup> The debate on GPS tracking of people is mainly focused on tracking children, spouses, or people with cognitive disorders such as dementia. When it comes to the latter, the debate represents many different perspectives. The stakeholders involved are people with dementia themselves (the patients<sup>93</sup>), (family) caregivers, relatives and friends, the patient's social contacts, manufacturers, the designers, health insurers, policy makers, accidental stakeholders (with or without use of GPS), the collective / society, future generations and

<sup>88</sup> United Nations, “Universal Declaration of Human Rights.”

<sup>89</sup> Bryce Clayton Newell, et al., “Privacy in the Family,” *Social Dimensions of Privacy: Interdisciplinary Perspectives* (2015): 113.

<sup>90</sup> There are also cases in which the three ethical concepts overlap to such an extent that it is no longer clear what exactly the core of the concern is. A relatively recent example from The Guardian shows how close safety and privacy can be related, if, for example, a man visits his wife in a care home and sees that she is allegedly sexually assaulted at an aged care home. The example shows how difficult it can be to get a grip on the ethical triangle in practice. Melissa Davey, “Husband walks in on wife being allegedly sexually assaulted at Sydney aged care home,” *The Guardian*, April 10, 2021, <https://www.theguardian.com/australia-news/2021/apr/11/husband-walks-in-on-wife-being-allegedly-sexually-assaulted-at-sydney-aged-care-home>.

<sup>91</sup> We must not forget that we can also be tracked by tech companies via our smartphone. Each smartphone is, in effect, a GPS tracker that we carry around. Carissa Véliz, *Privacy is Power: Why and how You Should Take Back Control of Your Data*, London: Random House, 2020, 7-8.

<sup>92</sup> Eltis, “Predicating dignity on autonomy—the need for further inquiry into the ethics of tagging and tracking dementia patients with GPS technology,” 394.

<sup>93</sup> Ann-Chatrin Linqvist Leonardsen, et al., “Patient experiences with technology enabled care across healthcare settings—a systematic review,” *BMC health services research* 20, no. 1 (2020): 1.



even the technology itself.<sup>94</sup> The debate, therefore, features various different disciplines and perspectives: the medical / care perspective, the technological perspective, the social perspective, the philosophy of technology perspective and the ethical perspective, the legal perspective, the economic perspective, the political or policy perspective, and so on. The different stakeholders are all represented here.

## 2.2 The ethical issues

Regarding the different stakeholders and perspectives in the debate, there is also a different emphasis on which ethical issues are central when it comes to the possible implementation of GPS tracking in EDLH care. The scope of this discussion is wide. I will highlight the most important considerations for the three most-discussed stakeholders: the people with dementia themselves, the (family) caregivers, and the designers.

Firstly, in the debate, different ethical values are at stake for the patient: autonomy, privacy and safety are often central when it comes to the patient's interests.<sup>95</sup> The discussion about autonomy includes claims that the use of this technology could support the independence of the person concerned.<sup>96</sup> Some authors say that GPS tracking supports freedom of movement.<sup>97</sup> Others see a tendency in the debate of the recognition of the need to compromise between autonomy and safety.<sup>98</sup> Privacy is also a frequently mentioned concern in the debate.<sup>99</sup> Karen Eltis, for example, expresses the concern that the privacy of people with dementia is being jeopardised by necessary convenience considerations of the caregiver.<sup>100</sup> Various authors, including Landau and Werner, emphasise the importance of consent by the people with dementia themselves and their involvement in the decision-making process.<sup>101</sup>

For caregivers, peace of mind is central.<sup>102</sup> Caregivers and family members are concerned about the safety of their loved one and the use of GPS technology could alleviate this concern.<sup>103</sup> Family caregivers can bear enormous burdens in caring for their loved one and their quality of life also deteriorates.<sup>104</sup> Authors recognise it is difficult to make the right trade-offs between the various ethical

<sup>94</sup> Peter-Paul Verbeek, "Ethiek en technologie," *Ethische perspectieven* 16, no. 3 (2006): 267-289.

<sup>95</sup> Yang, and Kels, "Does the shoe fit?" 1708.

<sup>96</sup> Niemeijer, et al., "The ideal application of surveillance technology in residential care for people with dementia," 305.

<sup>97</sup> *Ibid.*, 309.

<sup>98</sup> Yang, and Kels, "Does the shoe fit?" 1703.

<sup>99</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 364.

<sup>100</sup> Eltis, "Predicating dignity on autonomy-the need for further inquiry into the ethics of tagging and tracking dementia patients with GPS technology," 391.

<sup>101</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 358.

<sup>102</sup> Yang, and Kels, "Does the shoe fit?" 1710.

<sup>103</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 361.

<sup>104</sup> Sun, et al., "GPS Tracking in Dementia Caregiving," 3804.



values at stake.<sup>105</sup> For example, Alistair Niemeijer et al. see an inevitable and complex conflict between safety and freedom of the person with dementia.<sup>106</sup> Y. Tony Yang et al. argue that the values of autonomy, privacy, dignity, consent and patient safety may conflict with the peace of mind of caregivers.<sup>107</sup>

Finally, attempts are made in the debate to include ethical considerations in the designing process.<sup>108</sup> For example, Yao Sun et al. argue for a better understanding of the attitudes of the users towards GPS technology, to include their interests in the designing process.<sup>109</sup>

### 2.3 Two extreme positions to balance

Although there is a lack of extreme positions in the debate surrounding GPS tracking of EDLH, it may still be valuable to *imagine* two extreme opposing positions to see how we can find the right balance between the different ethical considerations in the debate.

One extreme position I will base on an argument formulated by Carissa Véliz.<sup>110</sup> Although her book *Privacy is Power* does not comment on GPS tracking for EDLH in particular, it nevertheless contains valuable considerations that may be useful in getting a grip on our own debate.<sup>111</sup> Véliz writes:

There are some surveillance technologies that are so dangerous, so fit for abuse, that it might be better to ban them altogether, just as we ban some weapons that are too cruel and hazardous. We should consider banning facial recognition, as well as gait and heartbeat recognition and other technologies that destroy anonymity – they are ideal tools for oppression.<sup>57</sup> [...] High-resolution satellites and drones are a third type of surveillance we should avoid.<sup>58</sup><sup>112</sup>

We could envision a similar argument for GPS tracking for EDLH: the extreme position that we should ban *all* surveillance technologies. GPS might be used in long-term care in combination with other types of e-Health such as heartbeat recognition and will therefore become increasingly susceptible to abuse. GPS technology also uses satellites, which may be worrying.<sup>113</sup> Who knows who could track your movements if your family decides to follow you via GPS? We can imagine serious privacy concerns here, which can strongly decrease people's capabilities in daily life.

<sup>105</sup> Niemeijer, et al., "The ideal application of surveillance technology in residential care for people with dementia," 303.

<sup>106</sup> *Ibid.*, 303.

<sup>107</sup> Yang, and Kels, "Does the shoe fit?" 1708-1709.

<sup>108</sup> Sun, et al., "GPS Tracking in Dementia Caregiving," 3805.

<sup>109</sup> *Ibid.*, 3806.

<sup>110</sup> Véliz, *Privacy is Power*, 154

<sup>111</sup> *Ibid.*, 1-268.

<sup>112</sup> *Ibid.*, 154.

<sup>113</sup> *Ibid.*, 154.



A recent example of the Dutch company Spotter shows how badly things can go wrong in practice.<sup>114</sup> When a data scientist gave her mother a GPS tracker so her mother could continue taking walks, she discovered a large-scale data breach, which allowed her to access the locations of all active Spotter users in the Netherlands and beyond within a few small steps.<sup>115</sup> Although it only concerned anonymous location data, and therefore no traceable identities linked to those locations, she was able to find the coordinates of the last 10 days of all Spotters.<sup>116</sup> This entails extreme privacy and security concerns. It allows malicious parties to see, for example, where children or vulnerable elderly people are, or, for example, that an elderly person is not at home for a while at certain times.<sup>117</sup> This case study shows how vulnerable we are when we depend on technology.<sup>118</sup>

Someone who takes an extreme position on this could respond by stating that the risks are too great to even consider using GPS technology. This possible *techno-pessimist* position argues for the prohibition and banning of all GPS technology in EDLH care.

A second extreme position, *techno-optimism*, is optimistic about the implementation of new technologies in healthcare. I will base this on the position taken by Stefan Lorenz Sorgner in his *On Transhumanism*, in which he defends his “weak variant of transhumanism”.<sup>119</sup> According to him, we must ensure an institutional recognition of emerging new cultural ideas such as those concerning transhumanism.<sup>120</sup> He argues that it is important to properly discuss and analyse new technologies in terms of the norms and values involved.<sup>121</sup> He states the following: “It is not a realistic alternative to close your eyes and demand that technological advances come to a halt.”<sup>122</sup> Sorgner says that technological progress will happen anyway and there is no point in denying it and closing ourselves off from it.<sup>123</sup> So, he thinks, it is important to talk about it properly.<sup>124</sup> Sorgner is not alone in holding such a position.<sup>125</sup> Peter-Paul Verbeek also believes that we are inextricably linked to technology and that we must learn to live with it in the right way.<sup>126</sup>

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<sup>114</sup> Laurens Verhagen, “Anne Rutten kon met een gps-tracker haar dementerende moeder volgen. En de rest van de wereld ook,” *De Volkskrant*, June 3, 2021, <https://www.volkskrant.nl/nieuws-achtergrond/anne-rutten-kon-met-een-gps-tracker-haar-dementerende-moeder-volgen-en-de-rest-van-de-wereld-ook~ba0402ee/>.

<sup>115</sup> *Ibid.*

<sup>116</sup> *Ibid.*

<sup>117</sup> *Ibid.*

<sup>118</sup> *Ibid.*

<sup>119</sup> Stefan Lorenz Sorgner, *On Trans-humanism*, trans. Spencer Hawkins (Pennsylvania: The Pennsylvania State University Press, 2020), chap. 5, Kobo.

<sup>120</sup> *Ibid.*, chap. 5.

<sup>121</sup> *Ibid.*, Introductory Remarks.

<sup>122</sup> *Ibid.*, Introductory Remarks.

<sup>123</sup> *Ibid.*, Introductory Remarks.

<sup>124</sup> *Ibid.*, Introductory Remarks.

<sup>125</sup> Peter-Paul Verbeek, *Moralizing technology: Understanding and designing the morality of things*, University of Chicago Press, 2011, 155.

<sup>126</sup> *Ibid.*, 155.



If we take this to the extreme under the guise of the techno-optimist position in the debate, it could contain the following. The techno-optimist believes that progress surrounding GPS trackers is inevitable and we must take advantage of this by fully deploying it in the care of all EDLH, so that we learn to cope with it correctly. The technology could increase people's capabilities in the future. We must also focus on prevention, and the techno-optimist thinks it is good to provide the elderly with

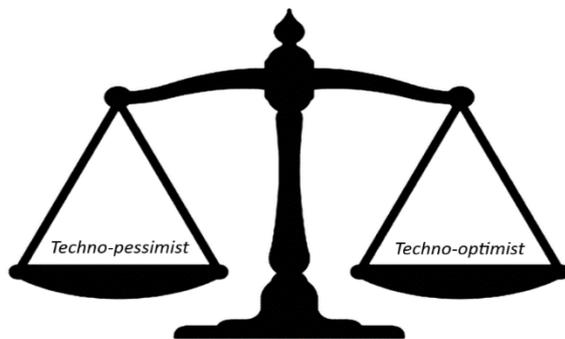


Figure 8

GPS trackers as a precaution. Later in my thesis I will show how we can find the right balance between the two extreme positions by means of a CA.

### 3. Patient perspective & consent

#### 3.1 Patient perspective & consent

There seems to be consensus in the debate that all interests of all stakeholders should be carefully considered in deciding on the possible implementation of GPS technology in EDLH care.<sup>127</sup> However, special attention is paid to the patient's perspective and involving them in the decision-making process.<sup>128</sup> Because it appeared to be difficult to make the right decisions in this regard, the authors consider it important to investigate what the demented person him or herself thinks about the possible implementation of GPS technology.<sup>129</sup>

The benefits of GPS tracking are being recognised, but privacy concerns remain an objection.<sup>130</sup> Yang et al. claim: "To some extent, advance planning can mitigate these concerns, wherein individuals willingly elect to be monitored before their impairments progress to a stage that makes such authorisation impractical."<sup>131</sup> They therefore find it important to involve the person suffering from dementia at an early stage in planning possible deployment.<sup>132</sup> They are not alone. Landau and Werner, similarly, argue that we should put the patient central in finding the right balance between the various ethical concerns:

<sup>127</sup> Yang, and Kels, "Does the shoe fit?" 1710-1711.

<sup>128</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 358.

<sup>129</sup> *Ibid.*, 358.

<sup>130</sup> Yang, and Kels, "Does the shoe fit?" 1708.

<sup>131</sup> *Ibid.*, 1708.

<sup>132</sup> *Ibid.*, 1708.



The decision whether, when and how to use GPS for tracking people with dementia should be made at the time of diagnosis jointly by the person with dementia, his / her family and professional caregivers.<sup>133</sup>

Yang et al. recognise that people with dementia at a certain stage are less capable to consent and participate in decision-making.<sup>134</sup> Within medical ethics we can interpret this as that from a certain stage the dementia patients are no longer able to provide informed consent, for example because they no longer have the competence to understand what the choice of GPS tracking is about.<sup>135</sup>

According to the World Health Organization, people with dementia go through the process in different phases.<sup>136</sup> Difficulty communicating, for example, is part of the middle stage.<sup>137</sup> The late stage is characterised, among other things, by reduced awareness of time and place and problems with recognising family and friends.<sup>138</sup> Problems with communication already make the shared decision about whether or not to use GPS technology difficult, let alone if the person with dementia no longer knows who he or she is talking to. Another trait already recurring in the middle stage is, according to the Alzheimer's Association, "showing an increased tendency to wander and become lost".<sup>139</sup> In practice, it often happens that the urgency of GPS technology that becomes visible through wandering behaviour only emerges when it is too late and good communication about the possible use of the technology is no longer possible. Accordingly, depending on the phase of dementia, we may not have direct access to their own patient perspective. While the patient perspective could be visibly safeguarded in other treatment situations by means of consent, this is sometimes different in the case of people with dementia. Seeking consent from the person suffering from dementia can be difficult if he is no longer able to do so due to his cognitive impairment.<sup>140</sup>

Another possibility would be to draw up an advance directive in which an elderly person determines whether or not he agrees to certain future treatments, such as GPS tracking, if he would get dementia.<sup>141</sup> The problem with this, however, is that people cannot know what it will be like to have dementia.<sup>142</sup> Getting dementia could be seen as being a transformative experience, if we use

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<sup>133</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 358.

<sup>134</sup> Yang, and Kels, "Does the shoe fit?" 1708.

<sup>135</sup> Beauchamp, and Childress, *Principles of Biomedical Ethics*, 124.

<sup>136</sup> World Health Organization, "Dementia."

<sup>137</sup> *Ibid.*

<sup>138</sup> *Ibid.*

<sup>139</sup> Alzheimer's Association, "Stages of Alzheimer's."

<sup>140</sup> White, and Montgomery, "Electronic tracking for people with dementia," 219.

<sup>141</sup> Beauchamp, and Childress, *Principles of Biomedical Ethics*, 14.

<sup>142</sup> Laurie Ann Paul, *Transformative experience* (Oxford: Oxford University Press, 2014), 16-17.



Laurie Ann Paul's definition of this, and we can therefore ask ourselves whether such advance directives are well-informed.<sup>143</sup>

### 3.2 Access to the patient perspective

Great importance is attached to the dementia patient's perspective. Various authors have attempted to contribute to the debate trying to gain insight into this. I will make a distinction between ethical and qualitative research.

In the ethical debate the authors mainly talk about the values that are at stake for the patient. These are the same ethical concerns we saw in section 2: freedom / autonomy, privacy, and safety.<sup>144</sup> Yang et al. and Landau and Werner suppose one way of dealing with the patient perspective is to seek consent of the person suffering from dementia.<sup>145</sup> In the ethical debate, consent therefore seems to be central. As we already saw, consent is a tricky issue depending on the stage of dementia. We need to seek it in a strategic manner, according to the authors. We saw Landau & Werner arguing in favour of seeking consent at the time of the diagnosis of dementia.<sup>146</sup> White & Montgomery also argue that prior to capacity loss proxy decisions must be arranged, which require early planning.<sup>147</sup> The decision-making process surrounding GPS technology must be well supported and clear information must be available.<sup>148</sup> They are also calling for more research into the patient perspective.<sup>149</sup> In the ethical debate about involving patients in the decision-making process for GPS tracking, I believe the argumentation is relatively abstract and focused on recommendations for further research. Is it a representation of how things are going in practice in the discussions regarding GPS tracking of EDLH?

It would be more concrete to ask demented people directly for their view and experience when wearing a GPS device.<sup>150</sup> This could gain insight into the patient interests that are considered of value by those involved in practice. Until a certain moment this has only been done to a limited extent, so there was still space to conduct more and larger-scale research into this up until 2018.<sup>151</sup>

But in the meantime, more qualitative research has been carried out which gives us direct insight into the perspective of (demented) elderly people on the possible use of GPS tracking for people

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<sup>143</sup> Ibid., 16-17.

<sup>144</sup> Yang, and Kels, "Does the shoe fit?" 1708.

<sup>144</sup> Ibid., 1710.

<sup>145</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 358.

<sup>146</sup> Ibid., 358.

<sup>147</sup> White, and Montgomery, "Electronic tracking for people with dementia," 230.

<sup>148</sup> Ibid., 230.

<sup>149</sup> Ibid., 230.

<sup>150</sup> Chiara Zucchella et al., "The multidisciplinary approach to Alzheimer's disease and dementia. A narrative review of non-pharmacological treatment," *Frontiers in neurology* 9, no. 1058 (2018): 8.

<sup>151</sup> Ibid., 8.



with dementia. Early in the debate, Landau et al. conducted research into who should make the decision, investigating the perspective of the caregivers but also elderly without dementia.<sup>152</sup> They say:

Whereas cognitively intact older people clearly differentiate between themselves and people with dementia, they support the use of tracking devices when dementia is either formally diagnosed or its signs are evident. They value the safety of people with dementia above preserving their autonomy. [...] The acceptability of tracking devices is dependent on their appropriate weight, size, and ease of use.<sup>153</sup>

Asking the elderly who may get dementia in the future would be one possibility to access the patient perspective. Safety and the involvement of the patient in the decision-making process are central according to them.<sup>154</sup> Lili Liu's research also shows a GPS acceptance based on the experiences of caregivers and people with dementia.<sup>155</sup> Annemarie Pot also finds the possibility of using GPS to be promising:

Almost half of the participants with dementia experienced more freedom and were less worried when they were outside unaccompanied, a quarter mentioned that they were more outside independently and a fifth that they had less conflicts with their caregiver after three months.<sup>156</sup>

McCabe's research shows people with dementia were enthusiastic about GPS technology, and the importance of including the dementia sufferers themselves in the design process.<sup>157</sup>

But other thoughts can also be found in the qualitative research.<sup>158</sup> Research shows how the patient perspective in the form of user-friendliness is central to the design of GPS technologies.<sup>159</sup> For example, research by Megges et al. shows that after four weeks the rating users gave to GPS

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<sup>152</sup> Landau et al., "Who should make the decision on the use of GPS for people with dementia?," 78.

<sup>153</sup> Ruth Landau et al., "What do cognitively intact older people think about the use of electronic tracking devices for people with dementia? A preliminary analysis," *International Psychogeriatrics* 22, no. 8 (2010): 1301.

<sup>154</sup> *Ibid.*, 1301.

<sup>155</sup> Liu, Lili, Antonio Miguel Cruz, and Don Juzwishin. "Caregivers as a proxy for responses of dementia clients in a GPS technology acceptance study." *Behaviour & Information Technology* 37, no. 6 (2018): 634-645.

<sup>156</sup> Anne Margriet Pot, Bernadette M. Willemse, and Sarah Horjus, "A pilot study on the use of tracking technology: Feasibility, acceptability, and benefits for people in early stages of dementia and their informal caregivers," *Aging & Mental Health* 16, no. 1 (2012): 127.

<sup>157</sup> L. McCabe, and A. Innes, "Supporting safe walking for people with dementia: User participation in the development of new technology," *Gerontechnology* 12, no. 1 (2013): 4.

<sup>158</sup> Herlind Megges et al., "Technology for home dementia care: A prototype locating system put to the test," *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 3, no. 3 (2017): 332.

<sup>159</sup> Hendrik Storstein Spilker, and Maren Kristine Norby, "Understanding the Role of Technology in Care: the Implementation of GPS-Technology in Dementia Treatment," *Ageing International* 44, no. 3 (2019): 285.



technologies decreased over time.<sup>160</sup> In another study it was stated that the dementia patient who was studied found the GPS tracker too large.<sup>161</sup> These and more articles show a completely different view of the dementia patient on the use of GPS technology. Why is it that, despite all the ethical and qualitative research, we still see little consensus? I will show that this has to do with the emphasis we place in the debate on a specific understanding of the central issue.

## 4. The need for a deepening of the debate

### 4.1 The need for a deepening of the debate

The debate about GPS tracking of EDLH is not optimal now. I see room for optimising it by examining in a different way what is at stake for the patient. I perceive two central problems regarding the discussion of consent in the debate.

First, several authors endorse the importance of seeking consent (preferably and when possible, at the time of diagnosis) and involving the elderly with dementia in the decision-making about GPS technology.<sup>162</sup> We immediately saw that the emphasis on consent can be problematic because consent is not always possible. While this is acknowledged by the authors in the debate, this does not solve the problem.

Perhaps, the implementation of GPS tracking should not depend on the diagnosis of dementia. Choosing diagnosis, we risk establishing incorrect classifications, which can be very problematic.<sup>163</sup> People could be hesitant about diagnosis on this basis, or, because they do not want to confront their loved one with the clinical picture of dementia while someone is already in a further stage, and this only unnecessarily burdens this person.<sup>164</sup> Another much-discussed reason is that diagnosis can be problematic because there is no effective cure for the disease.<sup>165</sup> I think that people should always have the choice not to have their loved ones diagnosed. If this choice is made, it becomes more elusive to state that we must strive for consent at the time of diagnosis. Even if there is no diagnosis, the technology can still be of value to those involved. It can therefore be problematic to consider consent surrounding the period of diagnosis a strict condition for the use of GPS technology.<sup>166</sup>

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<sup>160</sup> Megges et al., "Technology for home dementia care," 332.

<sup>161</sup> V. Fauconau et al., "Electronic tracking system and wandering in Alzheimer's disease: a case study," *Annals of physical and rehabilitation medicine* 52, no. 7-8 (2009): 579.

<sup>162</sup> Yang, and Kels, "Does the shoe fit?" 1708.

<sup>163</sup> Niklas Mattsson, David Brax, and Henrik Zetterberg, "To know or not to know: ethical issues related to early diagnosis of Alzheimer's disease," *International journal of Alzheimer's disease* 2010 (2010), 1.

<sup>164</sup> *Ibid.*, 2.

<sup>165</sup> *Ibid.*, 1.

<sup>166</sup> The concerns discussed here surrounding diagnosis might be cast in a different light with the approval of Aducanumab (Aduhelm™) for Treatment of Alzheimer's Disease. In view of the future when a working drug could possibly become available, this problematisation of diagnosis as described at the time of writing this thesis may no longer stand the way it is.

Although consent is definitely something we should strive for, I consider it worth it to explore alternative interpretations of the patient perspective. Qualitative research is already a good first step but does not suffice because of the limitations of each study and the lack of consensus that emerges. I do not strive to find a patient perspective that shows this consensus, because it is precisely the difference between patients that is central, but now we get too disparate yields of results that derogates the real interests of the patients.

This brings us to my second consideration. There is a concept that deserves more attention in the debate, namely freedom of movement. We need an approach that does more justice to the versatility of interests that converge in the patient perspective. I argue that a modern understanding of freedom of movement can provide us with the necessary new insights about the patient perspective. This will also help to weigh the other ethical values that are at stake for the patient.

#### 4.2 Freedom of movement & wandering

Freedom of movement is central to the interests of EDLH. If we go back to the core of the issue, we factually see that, because of their wandering behaviour, the freedom of movement of these people is starting to be at risk.<sup>167</sup> According to the UDHR, it is considered a human right to move freely, including people with dementia.<sup>168</sup> Especially for them, the ability to move and go outside is of extra and essential importance. I discuss three central reasons for this.

First, exercise, like walking, reduces the cognitive decline of people with dementia.<sup>169</sup> Wander behaviour is actually a very natural process with positive effects on the well-being of the EDLH.<sup>170</sup> This brings us to reason two. Being outside and making contact with nature are also important for people with dementia.<sup>171</sup> In fact, this is, according to Gilliard & Marshall: “[...] an innate need for all of us.”<sup>172</sup> This ties in with our third reason. Freedom to wander is important for the individual identity of people with dementia. Gilliard and Marshall state:

Many people, such as farmers and fishermen, have had a lifetime outside.

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Within this study, the consequences of this are not further discussed. “Aducanumab Approved for Treatment of Alzheimer’s Disease,” Alzheimer’s Association, last modified, 2021, <https://www.alz.org/alzheimersdementia/treatments/aducanumab-news>.

<sup>167</sup> United Nations, “Universal Declaration of Human Rights.”

<sup>168</sup> Ibid.

<sup>169</sup> J. Winchester et al., “Walking stabilizes cognitive functioning in Alzheimer’s disease (AD) across one year,” *Archives of gerontology and geriatrics* 56, no. 1 (2013): 96.

<sup>170</sup> Given this is an instrumental reason, the question arises whether cognitive decline could be reduced by other means as well. For instance, exercising at home, cognitive training or even some medicines. What makes being outside special? This takes us to the second and third more principled reasons because they elaborate on factors that could also help reduce cognitive decline (it stimulates the brain to make contact with nature or to go to familiar places, etc.).

<sup>171</sup> Jane Gilliard, and Mary Marshall, *Transforming the quality of life for people with dementia through contact with the natural world: Fresh air on my face* (London: Jessica Kingsley Publishers, 2011), 13-14.

<sup>172</sup> Ibid., 14.



For others, their activities outside are their consuming passion – for example, sailors, riders, walkers, and birders. For these people, their sense of self is profoundly related to the outside world. But then all of us spend a lot of time outside, even just doing everyday things like waiting for a bus or walking in the park, and for us too, our complete selves will include the experience of being outside. We would assert that people must remain in touch with nature to be whole beings.<sup>173</sup>

Individual identity is inextricably linked to how people relate to nature.<sup>174</sup> For people with dementia, individual identity is more of a concern than ever before, because they are in a process of amnesia and life change that can have a profound impact on their individual identity. It is therefore important to see the identity-related interests of people with dementia in relation to freedom of movement in nature and the world outside their home.

And it is not all about nature. For EDLH, it is also very important to be able to walk around in known areas. Their daily walk to the bakery can provide recognition, which can contribute to people being stimulated in their memory. This is important for the identity of these people. Besides, it is important for EDLH to continue to relate to other people; social contact is essential.<sup>175</sup> To guarantee this, it is important that EDLH can move around freely outside the home.

While wandering behaviour is often problematised, we now see that it is also a very natural, valuable, and healthy process for the demented persons him or herself. I therefore think it is worth arguing for a little more recognition for a positive view of wandering, without denying the concerns, but looking at how our understanding of wandering and the concerns can help us deal with it correctly.

One way to achieve this and to recognise a more positive attitude towards wandering behaviour, could be to investigate how wandering and freedom of movement relate in the research question, because freedom of movement can cover the benefits of wandering. For the ethical issues surrounding the use of GPS tracking for EDLH, it is therefore important to include the notion of freedom of movement in our considerations.

### 4.3 The need for a new understanding of freedom of movement

Freedom of movement is not only important in the discussion about the possible implementation of technological innovations in healthcare. It is a major topic in ethical and political-philosophical literature. An obvious association is John Rawls' discussion of "basic liberties" as part of his *A Theory*

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<sup>173</sup> *Ibid.*, 13.

<sup>174</sup> *Ibid.*, 13.

<sup>175</sup> Christine Stephens, "From success to capability for healthy ageing: Shifting the lens to include all older people," *Critical Public Health* 27, no. 4 (2017): 494.



of Justice and “two principles of justice”.<sup>176</sup> He states: “First: each person is to have an equal right to the most extensive basic liberty compatible with a similar liberty for others.”<sup>177</sup> There is a considerable debate about what those basic liberties are. Rawls lists the following basic liberties: political liberty, freedom of speech and assembly, liberty of conscience and freedom of thought, the right to hold (personal) property, and freedom from arbitrary arrest and seizure.<sup>178</sup>

Philip Pettit defends another theory of freedom.<sup>179</sup> You are free if you do not have someone who has a dominating power over you.<sup>180</sup> He sets two criteria in order to be called a basic liberty according to him: the criterion of co-exercisability and the criterion of co-satisfaction.<sup>181</sup> This means everyone should be able to exercise basic liberties and everyone should also be able to satisfy basic liberties, while everyone else can do that at the same time.<sup>182</sup>

Could such conditions also be relevant to our understanding of freedom of movement? Pettit describes:

The first criterion holds that any choice that deserves to be safeguarded should be the sort of choice that all the citizens of a society—roughly, all adult, able-minded, relatively permanent residents—can exercise, and exercise at more or less the same time.<sup>183</sup>

If we apply this “able-minded” condition to EDLH, does this imply that people with (severe) dementia are ruled out when it comes to basic liberties like freedom of movement?

In Sven Nyholm’s book review, we see a concern inherent to Pettit’s theory in this regard.<sup>184</sup> The first criterion does not explicitly attribute the same basic liberties to (and therefore might not apply to), for example, children and non-able-minded people (like people with dementia) as to adults and the able minded.<sup>185</sup> But to remain consistent in his theory, Pettit must either claim that non-able-minded people do not have these same basic liberties, but that would be undesirable, or Pettit must ascribe basic liberties to non-able-minded and children, for which he should broaden his theory from a focus on liberty as non-domination, to a division of focus over liberty and other concepts.<sup>186</sup>

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<sup>176</sup> John Rawls, *A Theory of Justice: Original Edition*, Vol. Original edition, Cambridge, Mass: Harvard University Press, 1971. <http://search.ebscohost.com.proxy.library.uu.nl/login.aspx?direct=true&db=nlebk&AN=282760&site=ehost-live>, 60-65.

<sup>177</sup> *Ibid.*, 60.

<sup>178</sup> *Ibid.*, 61.

<sup>179</sup> Philip Pettit, *On the people's terms: a republican theory and model of democracy*, Cambridge: Cambridge University Press, 2012, 22.

<sup>180</sup> *Ibid.*, 21-22.

<sup>181</sup> *Ibid.*, 93.

<sup>182</sup> *Ibid.*, 93.

<sup>183</sup> *Ibid.*, 94.

<sup>184</sup> Sven Nyholm, “Just Freedom?” *Res Publica* 20 (2014): 441-445.

<sup>185</sup> *Ibid.*, 444.

<sup>186</sup> *Ibid.*, 444.

In his approach to basic liberties, it is clear that Pettit does not offer enough recognition for dealing with non-able-minded people, such as people with dementia. He is not specific enough about this, which makes his theory not (yet) sufficiently suitable for our study which gives EDLH the leading role. The theory shows to be not all-encompassing regarding the interests of certain target groups like vulnerable people with a cognitive impairment, while we need an approach aimed at freedom of movement and well-being for everyone. For a correct interpretation of freedom of movement in the context of GPS tracking for EDLV, we need to go back to the core.

***“Freedoms are not only the primary ends of development, they are also among its principal means”<sup>187</sup>***

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<sup>187</sup> Amartya Sen, *Development as freedom* (New York: Random House, 1999), 10.

## 5. GPS tracking of elderly people with dementia living at home: a CA

### 5.1 The importance of the CA to our understanding of freedom of movement

We need to arrive at a new interpretation of freedom of movement for this thesis. I argue why the CA is very suitable and important for this.<sup>188</sup> It is a well-recognised theory of well-being which puts “freedom to achieve well-being” central.<sup>189</sup> It states that well-being consists in the so-called “capabilities” and “functionings” of people:

Functionings are ‘doings and beings’, that is, various states of human beings and activities that a person can undertake, such as being well-nourished, getting married, being educated, and travelling, while capabilities are the real, or substantive, opportunity that they have to achieve these doings and beings.<sup>190</sup>

The most well-known philosophers engaging with the CA are Martha Nussbaum<sup>191</sup> and Amartya Sen<sup>192</sup>.

The CA is relevant for investigating the fairness of GPS tracking for EDLH, for several reasons. Firstly, the central debate brings many different stakeholders and perspectives. For a theme of this magnitude, we need to use an approach that can bring these perspectives together.<sup>193</sup> I argue that we should not only use a multidisciplinary, but an interdisciplinary approach, because I think that in addition to identifying the differences, we should strive for a more comprehensive understanding of the topic by integrating different disciplinary insights.<sup>194</sup> In my view the challenge in practice lies most, as we see in balancing the two extremes, in including the technological and the policy & patient perspective (in the form of associated disciplinary research) in our considerations of deployment on a case-by-case basis. Interdisciplinary research is necessary to find the right balance between the two extreme positions. The CA can be characterised as an interdisciplinary approach. I therefore consider it very relevant for the research question.

The CA is particularly relevant to our understanding of freedom of movement, because freedom is a central and recurring theme within it.<sup>195</sup> The freedom of individuals to give meaning to life is exactly what matters when we talk about capabilities.<sup>196</sup> Furthermore, the CA is often associated

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<sup>188</sup> Robeyns, and Byskov, "The Capability Approach," 3.

<sup>189</sup> *Ibid.*, introduction.

<sup>190</sup> *Ibid.*, 2.1.

<sup>191</sup> Nussbaum, "Women's capabilities and social justice," 219-247.

<sup>192</sup> Amartya Sen, "Development as capability expansion," *The community development reader* (1990): 41-58.

<sup>193</sup> Eltis, "Predicating dignity on autonomy-the need for further inquiry into the ethics of tagging and tracking dementia patients with GPS technology," 395.

<sup>194</sup> Allen F. Repko, and Rick Szostak, *Interdisciplinary Research* (Los Angeles: Sage, 2017), 322-350.

<sup>195</sup> Sen, "Development as capability expansion," 44.

<sup>196</sup> *Ibid.*, 44.



with elderly's well-being.<sup>197</sup> This also applies to "the ability to do things" of the elderly, which includes walking, for example.<sup>198</sup> We see that capabilities are associated with the varying and complex identities of older people (which appeared to be important in section 4.2), in the form of people-place and people-people relationships.<sup>199</sup> We also see that the CA is often associated with technology, e.g. in the form of the Critical Capability Approach of Technology of Yingqin Zheng and Bernd Carsten Stahl, that is aimed at providing: "a set of principles that can be used to evaluate the design and impact of technologies".<sup>200</sup> This theory states that through a number of principles we can learn more about the desirability of technologies.<sup>201</sup>

Capability theory is separately associated with technology and the elderly. This together with the other factors makes the CA a valuable approach to the research question at first sight. Perhaps most importantly, it also offers room for a positive approach to wandering, because one does not think in terms of limitations but capabilities.<sup>202</sup> To understand exactly how this works, we will now focus on two specific forms of the CA: Martha Nussbaum's list of central human functional capabilities (CHFC) and, what I will call, a stage of life CA.<sup>203</sup>

## 5.2 Nussbaum's list of central human functional capabilities

I want to address a much discussed and well-known CA, to investigate how freedom of movement of EDLH can be understood in this approach and to create insight into the desirability of GPS tracking of EDLH, by examining whether it offers space for a positive approach to wandering. Nussbaum's theory has been used before by philosophers to discuss capabilities in the context of advanced dementia.<sup>204</sup> At first glance, this approach could fit in well with this topic.

Nussbaum has drawn up a list of CHFC, which have a political starting point.<sup>205</sup> She distinguishes herself from Sen, because Nussbaum focuses more on political entitlements than on wellbeing.<sup>206</sup> She has compiled the list based on an analysis of years of previous ideas spread across different cultures, and it is intended for individual interpretation per culture.<sup>207</sup> She encourages people

<sup>197</sup> Tim Schwanen, David Banister, and Ann Bowling, "Independence and mobility in later life," *Geoforum* 43, no. 6 (2012): 1317.

<sup>198</sup> *Ibid.*, 1317.

<sup>199</sup> Gopinath, "Thinking about later life," 259.

<sup>200</sup> Ilse Oosterlaken, "The capability approach, technology and design: Taking stock and looking ahead," *The capability approach, technology and design*, Dordrecht: Springer, 2012, 57-59.

<sup>201</sup> *Ibid.*, 73.

<sup>202</sup> Robeyns, and Byskov, "The Capability Approach," 3.

<sup>203</sup> Nussbaum, "Women's capabilities and social justice," 235.

<sup>204</sup> Catharina Melander, et al., "Human capabilities in advanced dementia: Nussbaum's approach," *International journal of older people nursing* 13, no. 2 (2018): e12178.

<sup>205</sup> Nussbaum, "Women's capabilities and social justice," 231.

<sup>206</sup> Robeyns, "Wellbeing, place and technology," 100013.

<sup>207</sup> Nussbaum, "Women's capabilities and social justice," 231.



to revise the list when necessary at any time.<sup>208</sup> Her list includes: 1) life, 2) bodily health, 3) bodily integrity, 4) senses, imagination, and thought, 5) emotions, 6) practical reason, 7) affiliation, 8) other species, 9) play, and 10) control over one's environment.<sup>209</sup>

The capability that immediately catches the eye regarding the research question is bodily integrity: "Being able to move freely from place to place [...]."<sup>210</sup> As we saw, people with dementia who tend to wander run the risk of being restricted in their freedom to move freely from place to place.<sup>211</sup> So in our theme, this capability is at risk. But there are more on this list that can help us understand what is going on for EDLH who tend to wander.<sup>212</sup> The bodily health<sup>213</sup> of these people is at stake, because we just saw in section 4.2 that wandering can also be very healthy. Senses, imagination, and thought are also important, because part of this is that people must be able to use their senses in a "truly human way", "being able to have pleasurable experiences", and to "avoid non-necessary pain".<sup>214</sup> These things are at risk when someone with dementia might not be allowed to go outside. For example, if someone is locked up in his house as a precaution, then the use of the senses in a "truly human way" is limited, as well as the possibility of having pleasurable experiences.<sup>215</sup> This person simply cannot function in a truly human way because we saw in section 4.2 that "being human" and the identity of an individual human being are inextricably linked to being outside and nature. Then 5, emotions: "being able to have attachments to things and people outside ourselves; [...]."<sup>216</sup> This is also essential for someone with dementia, and this too is not guaranteed without the use of GPS tracking. Another example 8), other species: "(being able to live with concern for and in relation to animals, plants, and the world of nature."<sup>217</sup> This ties in with another importance for EDLH, outlined in 4.2, namely contact with nature. More capabilities on Nussbaum's list apply to our theme, but I will not go into that for now.<sup>218</sup>

This list offers room for a positive approach to wandering because it makes us think in terms of entitlements of EDLH, rather than limitations.<sup>219</sup> If this list is universal, we need to find a way to guarantee these capabilities for everyone, including EDLH who tend to wander. Using Nussbaum's list of CHFC, we can argue for the empowerment of EDLH using GPS tracking, because this can ensure that they can (continue to) exercise their capabilities. For example, GPS tracking can help these people to

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<sup>208</sup> Ibid., 231.

<sup>209</sup> Ibid., 231-235

<sup>210</sup> Ibid., 232.

<sup>211</sup> Ibid., 232.

<sup>212</sup> Ibid., 231-235

<sup>213</sup> Ibid., 231-235

<sup>214</sup> Ibid., 232.

<sup>215</sup> Ibid., 232.

<sup>216</sup> Ibid., 232.

<sup>217</sup> Ibid., 232.

<sup>218</sup> Ibid., 231-235.

<sup>219</sup> Robeyns, "Wellbeing, place and technology," 100013.



move freely from place to place, which was one of the capabilities at risk. This could allow us to shift a little bit more towards the techno-optimist position on the line in our understanding of the patient perspective, which could argue for a partial justification of the use of GPS for EDLH.

### 5.3 A stage of life capability approach

Another tension in the capability literature that is directly applicable to our theme, is the discussion of capabilities belonging to different stages of life, like for the elderly.<sup>220</sup> The emphasis is on the well-being<sup>221</sup> and quality of life<sup>222</sup> of the elderly. Inspired by Michael Dunn, I will call this the stage of life capability approach (SLCA).<sup>223</sup> Central is that capabilities are age-related. For example, a child has different capabilities than adults and vice versa. Certain conditions are attached to claiming certain capabilities.

When it comes to EDLH, it is particularly interesting to look at the capabilities that apply to this stage of life.<sup>224</sup> However, people with dementia sometimes return to their childhood mentally and in their behaviour. Does that mean that the capabilities that are considered valuable for children also apply to these people? Katleen Gabriels warns against parental tracking of children.<sup>225</sup> She advocates monitoring concerns such as confusing parental care and control.<sup>226</sup> Is it plausible to advocate a similar caution in considering GPS technology for EDLH, who, like children, may be dependent on others in their well-being? While I consider this a highly relevant discussion to keep in mind, I will leave this subtopic for now.

Now let us look at how the literature talks about capabilities of the elderly. In table 1 I give an overview of the capabilities that are central to the later life of people, as observed by me in the debate about this.<sup>227</sup> For example, Christine Stephens states that security, enjoyment, and control contribute to quality of life according to the interviewed elderly.<sup>228</sup> Others put independent later life and mobility at the heart of discussing the interests of older people.<sup>229</sup> At first sight, this debate could be of great help in our understanding of the central issue. We want to better understand the patient perspective of EDLH in terms of freedom of movement and the SLCA can help us see how this relates to capabilities that are 'generally' thought to belong to elderly people.

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<sup>220</sup> Dunn, "Realizing and maintaining capabilities," S26.

<sup>221</sup> Schwanen, Banister, and Bowling, "Independence and mobility in later life," 1313.

<sup>222</sup> Stephens, "From success to capability for healthy ageing," 494.

<sup>223</sup> Dunn, "Realizing and maintaining capabilities," S26.

<sup>224</sup> *Ibid.*, S25.

<sup>225</sup> Katleen Gabriels, "'I keep a close watch on this child of mine': a moral critique of other-tracking apps," *Ethics and Information Technology* 18, no. 3 (2016): 12.

<sup>226</sup> *Ibid.*, 12.

<sup>227</sup> Dunn, "Realizing and maintaining capabilities," S26.

<sup>228</sup> Stephens, "From success to capability for healthy ageing," 494.

<sup>229</sup> Schwanen, Banister, and Bowling, "Independence and mobility in later life," 1313.



Table 1

**List of Later Life Capabilities (LLLC) <sup>230</sup>**

- Autonomy<sup>231</sup>
- Security<sup>232</sup>
- Independent later life<sup>233</sup>
- Enjoyment<sup>234</sup>
- Mobility<sup>235</sup>
- Healthy ageing<sup>236</sup>
- Social life (of your own choice)<sup>237</sup> social integration<sup>238</sup>
- Physical comfort<sup>239</sup>
- Identity<sup>240</sup>
- Contribution<sup>241</sup>
- Attachment to places<sup>242</sup>
- Control<sup>243</sup>

I claim that each of the listed later life capabilities can be increased for the elderly using GPS tracking technology. Physical comfort, healthy aging, mobility, social life (of your own choice), social integration, identity, and attachment to places can be safeguarded by using GPS tracking technology for the reasons mentioned above in 4.2. Autonomy, security, control, mobility, and independent later life are all capabilities that, according to the LLLC, belong to the elderly and of which we saw in the ethical triangle how GPS tracking can contribute to the promotion of these capabilities among EDLH. GPS tracking could also contribute to the promotion of enjoyment (which largely takes place outdoors and in interaction with the outside world), or contribution (which to a large extent takes place outside the home). To make all this possible while someone is, for example, in an advanced stage of dementia,

<sup>230</sup> This list is in random order.

<sup>231</sup> Shu, and Woo, "Use of technology and social media in dementia care," 110.

<sup>232</sup> Stephens, "From success to capability for healthy ageing," 494.

<sup>233</sup> Schwanen, Banister, and Bowling, "Independence and mobility in later life," 1313.

<sup>234</sup> Stephens, "From success to capability for healthy ageing," 494.

<sup>235</sup> Schwanen, Banister, and Bowling, "Independence and mobility in later life," 1313.

<sup>236</sup> Christine Stephens, Mary Breheny, and Juliana Mansvelt, "Healthy ageing from the perspective of older people: A capability approach to resilience," *Psychology & health* 30, no. 6 (2015): 715.

<sup>237</sup> Ruud Muffels, and Bruce Headey, "Capabilities and choices: Do they make Sen'se for understanding objective and subjective well-being? An empirical test of Sen's capability framework on German and British panel data," *Social indicators research* 110, no. 3 (2013): 1159.

<sup>238</sup> Stephens, "From success to capability for healthy ageing," 494.

<sup>239</sup> *Ibid.*, 494.

<sup>240</sup> *Ibid.*, 493.

<sup>241</sup> *Ibid.*, 494.

<sup>242</sup> Meijering, Van Hoven, and Yousefzadeh, "'I think I'm better at it myself'," 240 & Stephens, "From success to capability for healthy ageing," 494.

<sup>243</sup> Stephens, "From success to capability for healthy ageing," 494.



we need to recognise that GPS tracking can greatly contribute to this, because it allows people to still go outside in a relatively independent way.<sup>244</sup>

Just as Nussbaum's list, the LLLC also provides scope for adopting an optimistic attitude towards wandering behaviour of EDLH. This approach also focuses on how we can enable the elderly to meet their needs regarding freedom of movement, rather than on their limitations. The approach shows how we can support elderly people in their capabilities, by using GPS tracking. And again, it allows us to shift a bit towards the techno-optimist. The SLCA could argue for a partial justification for the use of GPS for EDLH.

## 6. Comparison of the two approaches

### 6.1 Criticism of Nussbaum's CHFC's applicability to this case

Both Nussbaum's CA and the LLLC provide relevant insights regarding freedom of movement when it comes to the patient perspective of EDLH who could be tracked. But which of these approaches is preferable? Is one of the two at all sufficient or should we remain critical and strive for a renewed understanding of freedom of movement understood from a CA?

Firstly, Nussbaum's CA clearly yields relevant insights, yet it does not suffice in our discussion of the central issue. It is good to realise that Nussbaum's approach, unlike the SLCA, focuses on people's political entitlements and justice, rather than wellbeing.<sup>245</sup> For example, all people must have a certain degree of capabilities listed by her, in order to call it justice.<sup>246</sup> I argue that political goals should not form the basis for discussing the capabilities of EDLH, because this would fall short of the concern of frailty of these people. Politics is not fundamental to this issue. We need more space for ideals in this particular case because we are talking about the interests of a significant and growing part of humanity. This is not about rights, but about providing EDLH with the most pleasant possible final stage of life. We therefore really need to talk about wellbeing.

Another widely recognised criticism is that we should not strive for a list of capabilities, because they should be variable.<sup>247</sup> For example, Sen refuses to make a list because he believes that this is not something that should be imposed top down by a philosopher.<sup>248</sup> We must beware of paternalism in this.<sup>249</sup> He thinks that a good list depends on context.<sup>250</sup> This makes it undesirable in my

<sup>244</sup> Landau, and Werner, "Ethical aspects of using GPS for tracking people with dementia," 358.

<sup>245</sup> Robeyns, "Wellbeing, place and technology," 100013.

<sup>246</sup> Oosterlaken, "The capability approach, technology and design," 6.

<sup>247</sup> *Ibid.*, 6.

<sup>248</sup> *Ibid.*, 6.

<sup>249</sup> Robeyns, and Byskov, "The Capability Approach," 3.3.

<sup>250</sup> Oosterlaken, "The capability approach, technology and design," 6.



view to apply it to GPS tracking for EDLH, because it is precisely in medical ethics and care issues, that we must prevent ideas that touch on paternalism. In this issue where the elderly are central, it is important not to impose things on these people that are not in keeping with the context in which they find themselves and that conflict with their individual identity.

Recall the example of Bernhard and Lewis. This showed that EDLH can differ substantially from each other. We should recognise that there may be different capabilities coming to the fore for different EDLH. We saw that it is important to make the choice for possible implementation of GPS tracking on a case-by-case basis. Nussbaum's list is too general for this. We need a CA that gives a little more direction in our context. The lack of contextuality and the abstraction of how the list is formulated means that we can better look at a different form of the CA in investigating the patient perspective of EDLH.

## 6.2 Critical appraisal of the SLCA to the debate

It is time to look at our second CA discussed, the SLCA. Where the CHFC were general in nature, the SLCA is specifically aimed at the capabilities of elderly. This could therefore meet exactly what was lacking in the CHFC. At first sight, this approach also yields relevant insights. It leads to the interim conclusion that there is room for an optimistic attitude towards wandering behaviour, which resulted in a small tendency towards techno-optimism and a partial justification of the use of GPS for EDLH.

Firstly, although the SLCA in this case is more desirable than Nussbaum's CHFC, because of, among other things, the emphasis on wellbeing instead of political entitlements, the SLCA is only partially sufficient in our case. A first possible concern about this is the fact that the approach is aimed at all elderly people and not those with dementia in particular, while very different capabilities may apply to this group than to 'general' elderly people. It is therefore not justifiable to make, without any consideration, statements based on the SLCA about the desirability of using GPS tracking for EDLH.

Secondly, the SLCA may not offer sufficient scope to cover the variation among the elderly (with dementia). The core of our issue to get a grip on the central theme is that we must look at what is desirable and justifiable for each individual. A correct approach must therefore offer room to be filled in individually, and the SLCA does not do this. Within this approach, the differences between demented people, such as regarding stage / type of dementia, complaints, and identity, cannot be sufficiently considered. It would not be justifiable to apply the list as it stands to the research question.

Finally, the SLCA does not say anything concrete about technology yet. In answering our central question, it is important to gain insight into what is at stake for the demented elderly it concerns in terms of capabilities, which is influenced using technology (namely GPS tracking). SLCA can teach us what is important for elderly, but it does not yet reconcile the influence of the older stage of life versus

technology on the capabilities of EDLH. This relationship between elderly and technology should be an essential starting point for our analysis, because there is still a lot of information and insight to be gained about this. We need to realise that technology has an influence on the capabilities of EDLH and we need a CA that explicitly recognises this.

In its application to GPS tracking of EDLH, the SLCA is not yet desirable the way it is now. Still, the theory is obviously not entirely useless for creating an understanding of the patient's perspective in the central theme, because it at least gives us a solid (debate-based) indication of what we could and should pay attention to. This makes the theory more useful than Nussbaum's and partially deployable for our purpose. How can we ensure that the useful insights of the SLCA can still be of value for creating insight into the possibility of implementing GPS technology for EDLH? What does it take to form a CA that offers emphatic recognition of the influence of technology on the capabilities of EDLH?

## 7. A plea for a Fused Capability Approach

### 7.1 SLCA enriched with a place-based capability approach

In this section we look for an alternative interpretation of the CA that *will* lead us to the right insights. One that offers emphatic recognition of the influence of technology on the capabilities of EDLH and can tell us whether this influence will tip the scales more towards the techno-optimist or the techno-pessimist.

I advocate a SLCA enriched with a place-based capability approach (PBCA), based on a recent article by Ingrid Robeyns.<sup>251</sup> This approach focuses on the understanding of the importance of place for wellbeing.<sup>252</sup> Robeyns states:

Some dimensions of wellbeing are constitutively place-related, such as “feeling at home”. Other dimensions of wellbeing are affected by what the places and locations in which we live mean to us. Taken together, we call them “place-based capabilities”. Using a capability account of wellbeing allows us to use social scientific research to investigate the role of social, economic, demographic, political,

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<sup>251</sup> Robeyns, "Wellbeing, place and technology," 100013.

<sup>252</sup> *Ibid.*, 100013.



ecological and technological processes on wellbeing.<sup>253</sup>

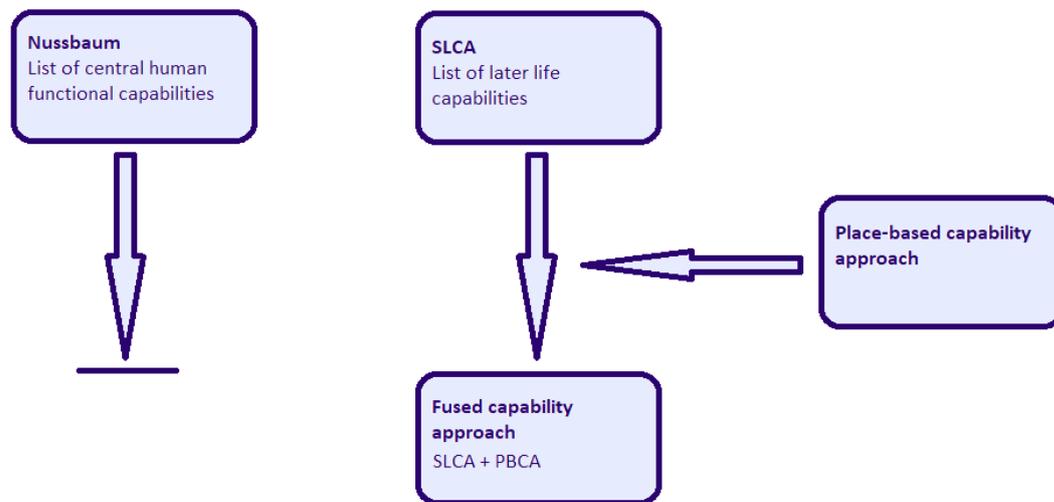


Figure 9

The starting point is to investigate the relationship between these “place-based capabilities” (PBC) and technology.<sup>254</sup> Technology can expand and enable PBC on the one hand.<sup>255</sup> On the other hand, Robeyns states: “[...] the use of those technologies has unintended consequences for other capabilities.”<sup>256</sup> I advocate an integration of this PBCA with the SLCA into what I will call a Fused Capability Approach (FCA), which I consider very suitable to apply to gain new insights into our research question.

## 7.2 Advantages of the FCA

The advantages of the FCA are clearly visible when considering the use of GPS tracking technology for EDLH. It provides us with the points that were lacking in Nussbaum's approach and the SLCA, but at the same time it still includes the benefits of the SLCA.

First of all, the FCA ensures that we both focus on the capabilities that generally apply to elderly people (which is more specific than Nussbaum's generalist approach), and at the same time take into account the differences between individual elderly people because of a focus on PBC, which are different for every individual, because places and feeling at home have a different meaning for every individual.<sup>257</sup> The SLCA has a demarcation that does not allow to be adjusted to every individual EDHL. We can do this with the FCA.

<sup>253</sup> Ibid., 100013.

<sup>254</sup> Ibid., 100013.

<sup>255</sup> Ibid., 100013.

<sup>256</sup> Ibid., 100013.

<sup>257</sup> Ibid., 100013.

In addition, the FCA allows us to see room for appreciation of and optimism towards the importance of PBC. It is precisely PBC that are central to EDLH. I explained this in detail in section 4.2, where we saw that the identity of EDLH is linked to being outside, nature or certain places in their environment. Capabilities can indeed be place related.<sup>258</sup> For example, a walk through the familiar neighbourhood can increase the capabilities of EDLH, because, for example, it has a stimulating effect on the brain and ensures healthy movement. The PBC central to the FCA makes the approach highly relevant for discussing the capabilities of EDLH.

Furthermore, the FCA offers an emphatic recognition of the influence of technology on the capabilities of EDLH.<sup>259</sup> This was still lacking in Nussbaum's approach and the SLCA. By including the PBCA, the FCA shows how technology can positively influence PBC, but also endanger other capabilities.<sup>260</sup> This brings us straight to where the FCA can be of value to us, as it covers and acknowledges all ethical concerns regarding GPS tracking of EDLH, including those within the ethical triangle. It offers us an opportunity to use an approach that recognises that the positive impact of technology on the PBC and wellbeing can have “unintended consequences” for other capabilities.<sup>261</sup> If the use of GPS tracking has a positive influence on the PBC of EDLH, for example because the technology ensures that the freedom of movement is preserved to a certain extent, then the FCA has in addition, an included recognition of the fact that a limitation of other capabilities can take place simultaneously.<sup>262</sup> Even if it is unintentional, strengthening the PBC of EDLH can ensure that their privacy or autonomy is restricted (in some other way). We need an approach that can include both the strengthening and narrowing of capabilities resulting from the technology in the analysis of the possible justification of GPS tracking for EDLH, and the FCA can do this. Only with an approach that can do the above-mentioned things, we can make considerations regarding our central theme in a justified way.

### 7.3 The two extreme positions revisited

In section 2.3 we saw an interest in presenting two extreme positions. The techno-pessimist argues for a ban on GPS technology for EDLH, while the techno-optimist argues that technological progress is inevitable and that we should take advantage of it by using GPS trackers for these people. I claim that the FCA can help us to balance and perhaps bring together all perspectives and therefore the two extreme positions.

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<sup>258</sup> Ibid., 100013.

<sup>259</sup> Ibid., 100013.

<sup>260</sup> Ibid., 100013.

<sup>261</sup> Ibid., 100013.

<sup>262</sup> Ibid., 100013.

The FCA sees value in technology for enhancing the capabilities of EDLH, without overestimating it because it recognises the possible negative consequences for other capabilities.<sup>263</sup> While it allows room for the optimism of the techno-optimist, the approach remains realistic and keeps us stable and balanced, like Plato's driver controls the surly horse, by seeing room to include not only the advantages but also the disadvantages. This keeps us closer to practice.

On the other hand, the FCA also does not allow privacy concerns to take over, as can be the case with the techno-pessimist, but instead presents it as a nuanced consideration. It shows that despite the optimism that we can have regarding technology in the possible implementation of GPS tracking for EDLH, there are a number of things to keep in mind. It is not only beneficial. Privacy can be one of the capabilities that is unintentionally influenced using technology, for example because of the aforementioned concerns that a GPS tracker can reveal sensitive information about someone which was not intended in advance.

The FCA allows us to strike the right balance between full commitment and prohibition. All this results in a well-founded yet reserved optimistic attitude towards technology when we use the FCA to gain insight into the influence of technology on the capabilities of EDLH.

#### 7.4 Why GPS tracking should be justified to a certain extent

Back to the research question: To what extent can the use of GPS tracking as a solution to wandering behaviour of EDLH be ethically justified from the point of view of a capability approach to the freedom (of movement), privacy, and safety that are at stake for the patient? Until now, I claimed that there is a need to examine the patient perspective apart from an emphasis on consent, to recognise the possibility of new insights. I showed that wandering behaviour is often (wrongly) problematised, while it can also be seen as a natural process which we should try to support EDLH in. We have an interest in mapping out the benefits of wandering. For this, it was necessary to create a renewed understanding of freedom of movement. I advocated for the FCA to achieve this.

The FCA shows that there is scope to clarify the positive influence of technology on the PCA of EDLH, without denying the possible negative influence on other capabilities.<sup>264</sup> The FCA also shows us that we can shift our stance on the central issue more towards techno-optimism, than how this has been visible in the debate so far, without compromising the concerns that play a role.

GPS tracking is a form of technology that, as discussed in the FCA, can ensure that EDLH are strengthened in their PBC, which we saw in section 4.2 are of great importance for this group of people. For example, the use of GPS can ensure that EDLH can continue to leave their house sometimes. They

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<sup>263</sup> Ibid., 100013.

<sup>264</sup> Ibid., 100013.



can go for a walk through their familiar neighbourhood to the bakery or walk past their old primary school around the corner. Because a safety factor is added to their daily lives, they may be able to stay home longer and therefore feel at home longer. The FCA allows us to see the positive side of wandering behaviour and it shows how technology can support the associated (place-based) capabilities such as freedom of movement. It shows the importance of GPS technology to PBC which are so important to EDLH. It teaches us that we should not be too reserved in discussing the possible deployment of such technologies.

We learn from this that with the help of GPS technology we can and should change our attitudes towards wandering because wandering can positively affect PCA, and technology can help us to react to wandering behaviour in the right way. We can also look at the patient perspective of EDLH in a different way than through a focus on consent. It results that the use of GPS tracking as a solution to wandering behaviour of EDLH can be ethically justified to a certain extent from the point of view of a FCA to the patient perspective, if this happens under a number of interdisciplinarily composed conditions that find a balance between the patient's freedom (of movement), privacy, and safety as part of the perceived ethical triangle, on a case-by-case basis. But I explicitly say, "to a certain extent", because despite the fact that I argue for a more optimistic attitude, we must set the right conditions for this that meet the capabilities that are unintentionally negatively influenced by the use of GPS technology.

## 7.5 The implications

The implications of my main thesis are present. I will first map the influence of the point of view on the debate, then the conditions that meet the unintentional negative influence the use of GPS technology has on other capabilities, and finally I map the practical consequences.

The thesis has resulted in a central point of view that attaches importance to deepening the meaning we give to freedom of movement and wandering when it comes to the patient perspective of EDLH. While this is emphatically not what I am arguing for (I am arguing for an enrichment of insights pertaining to the debate), it may be that the results the FCA has for our view of the patient perspective means that the emphasis in the debate is shifting from consent to freedom of movement. A new approach has been added to the debate and this may result in the various existing approaches having to hone in on the FCA, which may sharpen our view of the central issue. Our attitude towards wandering becomes more optimistic, which can also influence the tone of the debate.

The use of technologies such as GPS tracking to enhance PBC can have unintended negative effects on other capabilities of EDLH.<sup>265</sup> We have an interest in setting conditions that mitigate or even

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<sup>265</sup> Ibid., 100013.

prevent the effects on these capabilities, such as privacy (see section 1.5). Despite the claim that we can adopt an optimistic attitude towards GPS technology in our theme, there are a number of conditions to be met before we can legitimately use GPS tracking for EDLH. I have made the following list of conditions that align with different perspectives, in the order from the design process to the FCA.

Table 2

### Conditions

1. *Cases & the ethical triangle:*

The technology must be able to prevent dangerous situations, for example as outlined in Bernhard's case. That is, it contains only the necessary functions to ensure the safety and autonomy of the person it concerns.

2. *Technological perspective:*

GPS tracking may only be used if the technology is sufficiently developed. This is the case if: a) it has optimal effectiveness, b) it does not unnecessarily stigmatise because of its appearance, c) it is easy to use (not too heavy, no touch screen, etcetera).

3. *The minimum privacy perspective:*

In addition to the fact that the technology must work properly, the handling of the technology must also be ethical. Because neither the techno-optimist nor the techno-pessimist should prevail, but we do want to preserve the best of each, it is in our interest to only use GPS technology for EDLH if the information generated by the GPS device will not be used for commercial purposes. It namely is ethically important not to try to turn the dementia patient (or their (family) caregivers) into a customer (e.g., by targeted advertising) or into a source of income (e.g., as a data generator), because this would jeopardise the capabilities of these people to such an extent that the benefits of the technology for the capabilities of these people do not longer outweigh the disadvantages. Although this might be hard to achieve in practice, we can take it as something to strive for and this condition for implementation can help us do that. When it comes to the wellbeing of such a vulnerable group of people, it is important to aim for the most ideal scenario in this .

4. *Interdisciplinary perspective:*

GPS tracking may only be used if a careful consideration has been made beforehand, in which all different perspectives and the interests of all stakeholders involved have been recognised and taken into account.

5. *Policy and patient perspective:*

GPS tracking may only be used for EDLH if the interests of these individuals are sufficiently taken into account in the considerations by creating insight into the patient's perspective. The use of technology must not become the standard without there being any reason to implement it and without the specific interests of the individual having been mapped out within the given context. For this it is important that decisions are taken on a case-by-case basis. The technology must suit the individual (which will not always be the case) and may only be used if there are no other capabilities that are considered more essential in the view of the patient than the PCA to which the GPS tracker contributes.

6. *The FCA perspective:*

Even in cases where consent is no longer possible, there must be room for the environment of the person with dementia it concerns to make a correct assessment through the FCA with regard to the importance that is linked to the patient's perspective. This means that in some cases it must also be possible to use the technology without consent from the patient being possible. Now that we have seen that a focus on freedom of movement and a positive view of wandering is a justified way to get a grip on the interests of the dementia patients it concerns, this should become the starting point of the policy, when usual access to the patient perspective through, for example, consent is no longer possible. Everyone has a right to the technology.



The justification (to a certain extent) of GPS tracking for EDLH and the conditions have consequences in practice. I will illustrate this using Bernhard's case. Bernhard has dementia and we wonder: what if we had used GPS technology to track Bernhard's movements? Would that be desirable or is it better that people like Bernhard are not tracked and get to decide for themselves what they do?

In this case, the proper response might indeed be to give Bernhard GPS technology to track his movements. There are GPS tracking technologies that could have helped us avoid Bernhard's incident. However, we can only give him GPS trackers that work well and easily and do not have a stigmatising effect because of the appearance.<sup>266</sup>

But is it desirable to do this? It is important to discuss this not only with Bernhard, but also, for example, with Bernhard's wife, son, general practitioner, and caregiver so that their interests are also included. We should ask Bernhard for permission to use GPS, but if this is not feasible, we should try to learn more about his interests in an alternative way. In this thesis I explored an alternative approach to the patient perspective, which shows that we should be allowed to shift the tendency in the debate slightly more to techno-optimism, because GPS technology can strengthen the PBC that is so central to EDLH. For example, because it allows Bernhard to still go outside and perhaps even by car because this is now safer than without a tracker. It may allow Bernhard to continue living at home longer. In short, it is desirable that Bernhard is tracked to prevent incidents (if this is done under the right conditions). Bernhard can, to a certain extent, continue to determine for himself what he does, which might otherwise no longer be possible because, for example, he would be placed in a care home in which he has even less freedom of choice over his PBC.

## 8. Against a FCA to GPS tracking of EDLH

### 8.1 Possible paternalism

In this section, I discuss three concerns that could provide arguments against my thesis, and I will acknowledge, analyse and, where necessary, refute them. They are grounded in a concern about paternalism and the demarcation of my research.<sup>267</sup>

But first, what exactly do we mean by paternalism? Beauchamp and Childress define this:

*[...] as the intentional overriding of one person's preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefiting or of preventing or mitigating harm to*

<sup>266</sup> White, and Montgomery, "Electronic tracking for people with dementia," 224.

<sup>267</sup> Beauchamp, and Childress, *Principles of Biomedical Ethics*, 215-223.



*the person whose preferences or actions are overridden.*<sup>268</sup>

Critics may infer a concern that the partial justification of GPS tracking for EDLH (which is based on the FCA), which I advocate in this thesis, seems to lean towards paternalism. I have offered an interpretation of the patient perspective. I cannot empirically ground that this is really in the patient's interest. There is always the risk that with my position outlined, we impose something on EDLH.<sup>269</sup> Although the purpose of this may be to prevent safety risks and thereby harm to the person, it might override his or her own preferences.<sup>270</sup> Within this concern of paternalism, we can again distinguish two concerns.

Firstly, critics may think I am undermining the importance of consent from EDLH, which is so central to medical ethics and especially to such vulnerable groups.<sup>271</sup> I understand and acknowledge this concern. I would like to state emphatically that I am not in favour of replacing the notion of consent in approaching the patient perspective of EDLH for whom GPS tracking is being considered. In fact, I think consent should be the starting point. But I also want to give us the opportunity to centralise the patient's perspective in an alternative way, in cases where seeking consent is no longer possible, or where it becomes more complex because of a choice not to go for a diagnosis. We saw that there may be valid reasons why we cannot have access to the patient perspective of people with dementia in the form of consent, because this is not always possible, and it is often linked to diagnosis. I want to try to create insight into the patient's perspective in a different way so that this can be included as an aid when considering whether to use GPS tracking when consent is not possible.

My plea for a FCA is purely an addition to the debate to broaden and at the same time concretise our notion of the patient perspective within the central theme. This way, we do not have to focus on consent if that does not get us any further. Precisely if we do not offer room to approach the patient perspective in different ways, we risk undermining patients in their personal preferences and identity. This first concern about paternalism therefore does not hold in my view, although it is valuable to keep the concern in mind if we were to further investigate and develop my main thesis.

Another concern that could be expressed is that my approach could indicate underlying paternalism because I choose to focus on the capability freedom of movement and PBC, while I could also have focused on other capabilities or ethical concepts. Perhaps, I could also have chosen privacy to be my starting point for further exploring what exactly the patient perspective of EDLH encompasses. Perhaps we would see that privacy is actually the concept that is central to these people,

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<sup>268</sup> Ibid., 215-216.

<sup>269</sup> Ibid., 215-216.

<sup>270</sup> Ibid., 215-216.

<sup>271</sup> Ibid., 120-125.



for example because it is tied to their identity, generation, and personal ideas. It could have been the case that we could not have justified GPS tracking to some extent.

I understand this concern too. It demonstrates the complexity of the issue even further. While we should certainly keep this in mind, we should also realise that we are dealing with a highly applied ethical issue. So, decisions will have to be made. To provide as many people as possible with the right tools and information, I have considered it especially important for this thesis to create insight into what exactly is at stake for the elderly with dementia it concerns. I consider freedom of movement an essential part of our understanding of wandering behaviour. I have seen an interest in focusing within the scope of this thesis on the concept of freedom of movement and consequent PBC, to do justice to what I consider relevant and necessary to the issue in practice. I emphatically do not want to impose that freedom of movement is *the* concept on which we should base our considerations, but I do find it so fundamental to the issue that it is worth exploring further for in contexts where direct access to the patient's perspective is not possible.

## 8.2 A capability account of wellbeing

Third, briefly the concern that has to do with the demarcation of my research. A critic might argue that, instead of a capability account of wellbeing, we could also have opted for a different account of wellbeing, perhaps resulting in a different conclusion than a partial justification of GPS tracking of EDLH. For example, hedonistic theory focused on happiness, desire-fulfilment theories, or other objective list theories than the CHFC.<sup>272</sup> The objective list theories within the CA, such as Nussbaum's, are also often criticised for a possible paternalism that could underlie them.<sup>273</sup> Should not everything be done to prevent a paternalistic approach to research within a medical-care ethical issue such as GPS tracking for EDLH?

It is indeed true that we could also have investigated this issue based on other accounts of wellbeing. But the interdisciplinary nature of the CA, the way it puts freedom central, the fact that the CA is often associated with the wellbeing and complex identity of older people, which has arguably yielded great insights, and finally the fact that the CA turns out to be extremely suitable for analysing technologies, make me consider it justified using the CA to create insight into the central issue. This approach probably brings us the most when it comes to understanding freedom of movement and the significance of wandering behaviour for EDLH. Once again, I would like to emphasise that I do not claim to have used the right approach, but I consider this approach very suitable because it has proven to be

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<sup>272</sup> Roger Crisp, "Well-Being," In *The Stanford Encyclopedia of Philosophy* (Fall 2017 Edition), ed. Edward N. Zalta (ed.), <https://plato.stanford.edu/archives/fall2017/entries/well-being/> (accessed June 19, 2021), 4.

<sup>273</sup> Martha C. Nussbaum, *Women and human development: The capabilities approach*, Vol. 3. Cambridge University Press, 2001, 49-53.



very applicable and insightful regarding the ethical analysis of the possible use of GPS tracking for EDLH.

I recognise all the concerns, but at the same time I advocate that they be reconsidered. My central statement is purely aimed at seeking new insights focused on two parts of the debate that could be further explored: the importance of freedom of movement and our notion of wandering for our understanding of and respect to the patient perspective of EDLH.

## 9. Conclusion

Wandering behaviour is ubiquitous among EDLH. GPS tracking is a technology that can be used to track EDLH in their movements. This can help (family) caregivers to locate EDLH, if it is not known where he is because the person is lost, for example. My research question is: To what extent can the use of GPS tracking as a solution to wandering behaviour of elderly people with dementia living at home be ethically justified from the point of view of a CA to the freedom (of movement), privacy, and safety that are at stake for the patient?

We see how much elderly people can differ from each other regarding their progression of dementia and identity. This makes us realise that we have an interest in examining whether the use of GPS tracking can be justified on a case-by-case basis. Not only do we have to use the right GPS technology for this, but the perspectives of all stakeholders should also be considered. The perspective to which we have least easy access turns out to be the patient perspective of the EDLH. We must find the right balance between freedom / autonomy, safety, and privacy (the ethical triangle), in order to know whether the GPS tracking technology can justifiably be used to track EDLH in their movements.

No clear consensus has yet been reached in the central debate. What the various authors in the debate do agree about is the major importance attached to the patient perspective. Various attempts are made to gain insight into this. Where the importance of consent is often emphasised in ethical-theoretical research, qualitative research is also conducted into what (demented) elderly people think of GPS tracking. There is still room in the debate for the addition of a possible new approach that can provide us with insights about the patient perspective. This approach focuses on investigating and deepening the meaning of freedom of movement and wandering for EDLH.

To explore this, we need a new approach, the CA. Although Nussbaum's list of CHFC and the SLCA's LLLC may initially seem to help with this, it does not suffice. I argue for a SLCA enriched with a PBCA, which together form the FCA.

Using the FCA to answer the research question will show us that there is room for an attitude that leans slightly more towards techno-optimism, as it shows us that technology such as GPS tracking

can positively impact people's PBC which are central to EDLH, while at the same time recognising the negative influence on other capabilities. The FCA allows us to confirm and support the main thesis: The use of GPS tracking as a solution to wandering behaviour of EDLH can be ethically justified to a certain extent from the point of view of a Fused Capability Approach to the patient perspective, if this happens under a number of interdisciplinarily composed conditions that find a balance between the patient's freedom (of movement), privacy, and safety as part of the perceived ethical triangle, on a case-by-case basis. For the central statement to be justified, 6 conditions must be met. In short, 1) the technology must be able to prevent dangerous situations, 2) it must be well developed, 3) the information generated by the GPS device should not be used for commercial purposes, 4) the interests of all stakeholders and perspectives must be taken into account, 5) the patient must be central, and 6) even if consent is no longer possible, there must be room to gain insight in a different way into the possible importance of GPS technology for the patient, understood in terms of PBC .

I elaborately discussed the implications of my statement on the academic and social debate, and practice, in section 7.5. With my FCA I hope to be able to contribute to focusing the terminology we use to talk about whether to use GPS tracking technology for EDLH. Because the FCA has given us a better idea of what freedom of movement and wandering could mean for patients, this can make the discussion between all stakeholders more meaningful and promote the discussion in practice. In section 8 we see that my FCA to the research question also suffers from a number of limitations, which are all important to keep in mind, but they are no reason to question the main thesis.

There are, however, several points related to the limitations of my research, which could provide a good basis for further research. For example, in my research I did not focus on creating insight into the perspectives and interests of all stakeholders. I purely looked at whether the use of GPS technology can be justified in the interest of EDLH, because we have had the most limited access to this. Possibly, the new insights the research has provided about the patient perspective can help making trade-offs between the interests of all stakeholders. In follow-up research we could investigate their perspectives. For example, we could ask ourselves what the significance of GPS tracking is for the autonomy and freedom of movement for the family of EDLH.

Another limitation is that I focus on today's elderly. But the elderly of today are not the elderly of the future. Perhaps, PBC are of much less importance or are of a very different nature for future EDLH, because, for example, they have moved more often in their lives. I expect that new research into the patient perspective of these people is needed in the future.

In the introduction I indicate that I emphatically do not focus on the influence of the corona pandemic on the possible justification of GPS tracking of EDLH because this would change the nature of the issue too much. Follow-up research could be based on the insights that the pandemic has

provided regarding our research question. For example, how does social and physical distancing affect the situation of EDLH who tend to wander? Are there more reasons to track these people because they are more likely to endanger the safety of themselves and others due to the risk of corona disease transmission?

Finally, wandering has a different meaning in an environment where it is not recognised and acknowledged. EDLH who live in a village may be a well-known customer at the bakery, but the same person can go through life anonymously in the city. This requires a different approach and therefore also a different consideration of whether to use GPS tracking. We must keep in mind that my FCA is not all-encompassing and that the conditions that result from it can and should of course be adapted for each context, just as this is central to the CA. One way to gain insight into this could be to conduct research into the location and context dependence of PBC.

The debate about GPS tracking of EDLH is rich when it comes to the number of stakeholders, disciplinary insights, perspectives, and interests. I have attempted to elaborate on a very important perspective, namely the patient perspective, hoping to help the debate develop further. The conditions and suggestions for follow-up research offer a good first step towards further investigating the justification of a move towards GPS tracking technologies used for EDLH.

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