BELGIAN ADVISORY COMMITTEE ON
Bioethics

Opinion no. 56 of 16 December 2013 on expedients for wandering detection of people with dementia in home care situations

I. The request for an opinion

I.1. Introduction

In a letter dated 4 July 2011, Flemish Minister of Welfare, Public Health and Family Affairs, Mr Jo Vandeurzen requested the *Belgian Advisory Committee on Bioethics* to put forward an opinion regarding the ethical limiting conditions for using expedients for wandering detection of people with dementia. His request comes as part of his policy plan on dementia, *Het Dementieplan Vlaanderen 2010-2014 (The 2010-2014 Flanders Dementia Plan).* [1] In his letter, the Minister states that he is looking to focus on care technology. His intention is to commit technological expedients to promote the self-reliance, the sense of comfort and the social inclusion of people with dementia. By the same token, he is looking to use the new assistive technologies to help support home care. However, he is duly aware of the ethical issues involved:

> "New expedients, such as 'tagging' via GPS, the use of chips in ankle tags, etc. may be considered as a form of restraint. Moreover, there is the risk that the use of expedients relegates the search to acquire an understanding of the reasons for wandering or absconding behaviour in amongst other things to the background. Obviously, new expedients are merely tools and resources at the service of the safety and quality of life of the person with dementia."[2]

The Minister concludes that the ethical limiting conditions for the use of expedients for wandering detection need to be set out, which is why he has invited the *Belgian Advisory Committee on Bioethics* to deliver an opinion on the matter.

I.2. The context of the request for an opinion

As stated, the context of the request for an opinion is the 2010-2014 Flanders Dementia Plan. The plan places central the self-sufficiency of those in need of care and their home environment.

Contrary to what is widely believed, the majority of people with dementia receive care in their home setting. In Flanders this applies to around 65% of those affected by dementia. The Minister is looking to further stimulate this type of home care. All the more so as home care meets a number of basic principles that are highlighted as priorities in the *Dementia Plan*. People with dementia are entitled to social citizenship, which implies that they need to be allowed to partic-

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[1] *Naar een dementievriendelijk Vlaanderen. Dementieplan Vlaanderen 2010-2014 (Towards a Dementia-friendly Flanders. 2010-2014 Flanders Dementia Plan).* Cabinet of Flemish Minister of Welfare, Public Health and Family Affairs Jo Vandeurzen, Record **1201** (2010-2011) – No. 1. Hereinafter abbreviated as DPV.

[2] Letter from Jo Vandeurzen, Flemish Minister of Welfare, Public Health and Family Affairs to the Belgian Advisory Committee on Bioethics dated 4 July 2011 on the ethical limiting conditions on the use of expedients for wandering detection of people with dementia.

ipate in their regular family and social setting for as long as possible.[3] As such, the plan is in keeping with the pleas by authors such as Kitwood and, more recently, Barlet and O'Connor to throw open the conventional views on dementia. "It needs to move beyond seeing the individual person as a passive care recipient to seeing the person as an active social agent in the broad context of their lifestyle, life course, social networks and community activities."[4] Rather than considering people with dementia as isolated individuals in need of care, the Minister is aiming for a multidimensional approach that acts to crack open the misleading homogeneous view of dementia whilst showing the greatest possible respect for the individual situation and the potential of each individual person. In doing so, the Minister is looking to encourage tailored care in observance of the identity-defining nature of a person's specific social position, concrete home situation and life stage for as long and as best as possible. In order to promote the social citizenship of people with dementia, the Minister is keen to encourage people with dementia to remain socially involved for as long as possible. Furthermore, the plan opts for the societilisation of care,[5] for the integration of the delivery of all types of care (administrative, organisational, financial, clinical), for a greater focus of attention on care and counselling needs and for respect for the dignity and integrity of people with dementia.

The third paragraph 'Wonen van en voor personen met dementie' *(Residential arrangements of and for people with dementia)* of the fourth chapter of the *Dementia Plan*: 'Versterking van de autonomie van de persoon met dementie en zijn mantelzorger' *(Strengthening the self-reliance of the person with dementia and his family carer)* emphatically points out the development of technological opportunities in support of home care. Given the commitment of the Flemish Government for the *Flanders' Care* forum, which is intended to foster technological innovation in the care sector, it is obvious that the Minister is looking to create room for innovation. However, the plan also states that the introduction of new technological applications is not permitted to encroach on a single aspect of the delivery of care. Setting out from a pilot scheme that sought to examine the possibilities brought by ICT for the home care for people with dementia, the Minister is duly aware that the collaboration between the care sector and the technological sector is not a matter of course.[6]

Among the aims and actions proposed under the plan in respect of residential arrangements of

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[3] DPV, p. 21.

[4] R. Barlet, D. O'Conner, *Broadening the Dementia Debate. Towards Social Citizenschip*, Bristol, Policy Press, 2010, p. 4. See also: T. Kitwood, *Dementia Reconsidered*, Buckingham, Open University Press, 1997. Kitwood's proposed new approach has chosen the comfort, identity, commitment, integration, bonding and the love of a dementing person as its point of departure (p. 82).

[5] "This principle also requires people with dementia to be enabled to build a 'life that is as normal as possible' in our society." DPV, p. 21.

[6] This was the *E-Tandem Live Project* which was rolled out in two phases (2006 and 2007). The scheme was intended to make electronic equipment available to people with dementia and family carers to pass on information, facilitate communications with other caregivers and ensure the safety of the residents (smoke/fire detection, burglary detection, passive and active person detection, wandering detection, camera surveillance, video communications with a central incident room) by way of sensors, video phone communications and cameras. cf. *Verslag E-Tandem, Project Thuiszorg 2005 (E-Tandem, Project Home care 2005 Report)*, Expertisecentrum Dementie Turnhout *(Turnhout Dementia Expertise Centre)*; *E-Tandem Live project*, Turnhout Dementia Expertise Centre, 2007. We will return to this pilot scheme elsewhere in this document.

and for people with dementia, the intent to solicit the *Advisory Committee on Bioethics* to deliver an opinion on the ethical limiting conditions with regard to expedients for wandering detection (DPV, p. 62) is preceded by the thesis:

> "The further introduction and perfection of ICT-controlled tools such as telemonitoring, multi-sensoring of patient parameters or advanced home automation, will allow care recipients to continue to live in their own homes. Focusing on care technology is intended to strengthen care recipients' self-reliance, raise their sense of comfort and ensure enhanced social inclusion. In addition, these technologies enable the delivery of better support for caregivers and family carers through the improved gathering and transmission of information." (DPV, p. 61)

I.3. Specification of the request for an opinion

The context of the request for an opinion shows that the Minister is chiefly focusing on the limiting conditions for wandering detection within the context of home care.[7] There is no express request for an opinion on the limiting conditions of wandering detection in a residential setting.[8]

In regards to the nature of the technology: the actual request relates to wandering detection technology. Strictly speaking, other ICT applications which may help ensure the safety of care recipients (ICT tools in the areas of fire or burglary prevention, passive and active person detection, communications with outside caregivers for instance) do not come within the scope of the request for an opinion.

What does wandering detection technology consist of? ICT applications in the area of wandering detection are fairly diverse. Wandering detection systems appear to differ depending on what it is one hopes to achieve by employing these systems.

In residential care, the technology is first and foremost committed for the purpose of surveillance. These technologies usually involve a set of tools including a position badge (integrated into an armband or an ankle tag for instance); a series of transmitters that transmit signals from a fixed location on the basis of which the position of the position badge may be inferred and a receiver that is fitted on an Ethernet LAN connection that processes the signals from the various transmitters. This set allows the carers or an on-duty service to be alerted and/or the outside doors to be shut automatically when people try to leave the institution.

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[7] The 2010-2014 Flanders Dementia Plan defines the aim of the use of technological expedients as: "to raise the self-reliance, sense of comfort and social inclusion of people with dementia within their familiar social setting."

[8] The report of the Ministerial Explanatory Memorandum of the Dementia Plan submitted on Tuesday 31 May 2011 to the Committee for Welfare, Public Health, Family Affairs and Poverty Policy: The minister "is looking to focus on care technology and ICT, with a specific focus of attention made to go out to *wandering detection in the home setting*, for instance with a missing persons protocol between the police and caregivers." (our italics).

These types of systems are often combined with systems that alert staff when a resident has a fall or gets into trouble.[9]

These types of surveillance systems can be used *in a home care setting too*. However, in this context, an entirely different type of wandering detection system is being developed, whose principal aim is not to prevent people with incipient dementia from leaving their familiar environment. If anything, these systems are meant to enable people with incipient dementia to do their own shopping, go out for walks or visit friends and family for longer, without these people themselves, their relatives or family carers having to be concerned that they might end up getting hopelessly lost and end up in trouble at times when they get confused. In The Netherlands, what is usually used in these circumstances is something referred to as the 'zorgriem *(care belt)*'. This system usually involves the combination of a GPS (*Global Positioning System)* and a mobile telephone which is carried by the person with incipient dementia allowing the family carer (usually the partner or a family member) to establish where the person concerned finds himself by way of a password-protected Internet application. By pressing a preset button on the device, the person concerned is able to directly reach the family carer and vice versa. The family carer can speak to the patient via a loudspeaker on the device. In doing so, people who get lost can be reassured by their nearest and dearest or assisted to find their way back, be picked up or taken home by an outside service.[10]

It goes without saying that the purpose for which a wandering detection system is committed is determined by the condition of the person with dementia for whom the technology is intended.

If dealing with people in the first stage of Alzheimer's disease, the technology will first and foremost be used to locate the person with dementia in case of problems. This technology allows the patient to leave his own home/residence to go out shopping, enjoy leisure activities or maintain social contacts, without the patient himself or his family carer having to fear that he will not be able to find his way home[11]. The wandering detection tool is used only at times when grounds exist to suspect problems may arise. In these situations, the patient's freedom of movement is ensured as the surveillance feature is used only for emergency situations.

When dealing with people with advanced dementia, the purpose is to prevent patients from going astray, at which point the system involves a constraint of the freedom of movement so as to protect the safety and physical integrity of the patient. The moral and legal issues that arise at this point are entirely different in nature. Here, thought will need to go out to the crite-

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[9] These types of systems are available from FSE Turnstyles bv, Televic healthcare, etc.

[10] Cf. http://www.zorgriem.nl The system was tested by the Trimbos Institute, the centre of expertise on mental health care in The Netherlands.

[11] For the purpose of the present opinion, it was decided to use general terms such as "the person with dementia", "the partner" or "the patient" and references to these persons as "he" or "she" in the interests of the legibility of the text. Needless to add these terms relate to both men and women.

ria to put in place freedom-constraining measures, to the conditions in respect of the condition of the patient or the risks to be avoided, the nature of the means brought to bear, the decision-making procedure, who is allowed to make the decision (the nursing staff, the attending physician or a judge?), the people that need to be consulted, the way in which the decision is to be formalised, the practical conditions governing the way in which control is to be exercised, etc. The present opinion does not dilate on these matters as the issue of the deprivation of liberty in a care context transcends the issue of the commitment of wandering detection systems.

The present opinion on the limiting conditions for the implementation of wandering detection technology consequently relates to wandering detection systems that involve the use of a GPS to notify family carers and/or an on-duty service by way of a password-protected site of the location of the person in their care when he is out of the house.

Alongside the use of electronic expedients, there are also alternative strategies that can help confine the problems experienced by people with dementia when erring and going astray. As part of the preparations, the working group found out more about the scheme put in place by the HEKLA regional police authority (Hove, Edegem, Kontich, Lint and Aartselaar) in association with the regional *Orion* Dementia Expertise Centre in Wilrijk. The police authority of the HEKLA region put in place arrangements with care centres that rank people with dementia among their residents, provided training courses for their staff and set up a protocol in joint consultation with expertise centres, field experts and care workers. The main idea is to encourage private citizens and institutions to draw up a document for each person who has a risk profile, which is kept by family carers or by the care centre at an accessible location. At the time the patient goes missing, a procedure gets under way whereby the family carers or the care workers first conduct a systematic search of the patient's own home or the residential institution. After a search period of 20 minutes maximum, the document containing concrete details is transmitted (by fax or e-mail) to the police further to a prior telephone call. In response, the police immediately sends out a patrol on-site whilst the track & trace scheme is initiated. The document contains all relevant details that could be useful to track and trace the patient. This document is provided to the police only when the patient goes missing.

The results of this project were positive and it was insisted for the scheme to also be implemented at other regional police authorities. HEKLA regional police authority Chief Inspector Mr Crabbé stated that the use of electronic resources could obviously act to make the tracking and tracing of people with dementia who have gone astray a lot easier still.

II. The concept of 'dementia'

Definition

Dementia is typified by the impairment of a person's mental faculties (memory, abstract thought, judgement), changes in personality and functional impairments (aphasia, apraxia, agnosia). These impairments result in the disruption of professional and social activities and of interpersonal relationships. They involve a significant deterioration compared with the patient's previous level of functioning. The symptom complex cannot be explained by any other clinical disorders (depression or schizophrenia) or a delirium.

The frequency of dementia is seen to rise with age. Around the age of 65, 0.5% of the population is affected by dementia. This prevalence increases up to 15 to 20 % among 80-year-olds and up to over 30% among people over the age of 85. However, dementia is not a 'normal' sign of old age. Dementia is a disorder, or to be more precise, dementia is a syndrome which may be caused by a variety of different illnesses.

The cause of dementia can be examined only in the initial stages of dementia. As the disorder progresses, greater portions of the brain are affected; the deviations that are typical of certain types of dementia consequently become increasingly less numerous to the point that it becomes increasingly more difficult to establish the exact type/nature of dementia.

Over half of dementia cases (around 60%) are caused by ***Alzheimer's disease (AD)***. Clinical features throughout the various stages are described elsewhere in this document.
Vascular dementia represents around 15% of the causes of dementia. In some 20% of cases, an overlap is said to exist between vascular dementia and AD. The cause of vascular dementia lies in a string of cerebrovascular ischemic accidents (an embolism or arteriosclerosis). This form of dementia is typified by a sooner gradual course of the disease, as a result of which the patient may experience protracted episodes of relative lucidity more often. These patients are frequently seen to be affected by focal neurological deficits.
Presumably around 5 to 15% of dementia syndromes are typified by **Lewy bodies**. This form of dementia largely involves extrapyramidal symptoms, fluctuations in alertness and cognitive faculties and (visual) hallucinations (formed and recurrent) coming to the fore. An important deficit in the cholinergic system is at the origin of this disorder.
Less frequent in around 1 to 10% of people with dementia and primarily in the somewhat younger population (under 70s) is the diagnosis of **frontotemporal** dementia. Here we chiefly see changes in character, behavioural impairments, impairments in abstract and executive functioning, mental rigidity, perseveration and stereotypical behaviour.

Diagnostic examination for cognitive impairments is important given the fact that, in a limited number of cases, cognitive impairments are the result of treatable disorders such as *normal pressure* hydrocephaly, brain tumours and infections (encephalitis). Metabolic defects such as thyroid diseases, vitamin deficiencies (B12), anaemia, electrolyte impairments and intoxication with medicines may cause cognitive faculty impairments. Usually this type of examination is performed by the primary care physician. In some cases, further specialist examination is required. But even then, especially in the initial stages of the disease, doubts may exist over the diagnosis, requiring a wait-and-see stance, with an assessment performed a few months later[12].

The clinical characteristics of Alzheimer's disease depend on the stage the disease is at.[13] [14]

Incipient dementia

People with incipient dementia are increasingly more forgetful. They are no longer able to conceal this from those around them. They lose their self-confidence. Which is why this phase is sometimes also referred to as the ‘threatened I’ phase: patients become ham-fisted, find they start making linguistic gaffes and experience loss of self-control, but are sadly unable to do anything about it. Depending on their personality, those affected are made to contend with anxieties, feelings of gloom, sadness, irritability or anger. They lose interest in others. As they still have a better recollection of experiences in the more distant past, they start living in the past. During this phase, guidance and supervision are needed. Usually, patients are still self-reliant during this stage as far as everyday activities go. Spatial and temporal disorientation may occur but tends to be sooner intermittent.

Moderate dementia

The memory problems gradually get worse. People with moderate dementia stop remembering new things. Experiences that occurred slightly longer ago too become a struggle to recall. They start losing awareness of time, lose their way and stop recognising themselves or other people. The world becomes chaotic: past and present are seen to blend and interweave. Patients with moderate dementia get increasingly disoriented and get lost in their own life history, their own body, their experience of self, the environment that used to be familiar to them. Their behaviour becomes disoriented: they go off wandering, start collecting items and repeating actions. Everyday activities such as eating, getting dressed and getting washed require assistance.

Severe dementia

When they reach the severe dementia stage, patients are no longer able to fend for them-

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[12] National Guideline Clearinghouse: http://www.guideline.gov/content.aspx?id=34444
[13] www.alzheimerliga.be/dementie?INFO
[14] www.omgaanmetdementie.be

selves in any meaningful way. They need assistance or nursing care with just about everything. The person with dementia becomes bedridden and completely withdraws within himself. It is as though he is returning to his first few years of childhood. His existence is entirely directed by gratifying his basic needs: sleep, food and drink. Life is slowly slipping away. During this stage of dementia, contact with the patient is chiefly physical. People with dementia also continue to remain sensitive to emotional stimuli (such as agitation, sadness) in the people around them for a very long time.

Not all people go through this process in the same way. Even in one and the same person, the course of the disease and the symptoms may be subject to strong and unpredictable fluctuations.

Treatment of people with dementia

Treatment of cognitive faculty impairments

The way in which dementia is tackled continues to remain strictly symptomatic for now. A temporary improvement of the cognitive impairments is seen with acetylcholinesterase inhibitors and the NMDA receptor antagonist memantine in around half of people with dementia. Alongside a limited effect on cognitive faculties, these may possibly also have an effect on functional and behavioural impairments.

Treatment of behavioural impairments

As a first course of action, it is important for the behavioural impairments to be addressed without the use of medication (see 'Counselling programmes' below). The search for strategies that enable elderly people with dementia to keep their dignity for as long as possible are extremely important. In exceptional cases, a treatment with neuroleptics and/or benzodiazepines) may be advisable.

Treatment of affective impairments

A great many people with dementia go through a depressive episode in the early days. Incipient dementia is often impossible to distinguish from depression. In these circumstances antidepressants may be advisable.

Counselling programmes

Through multidisciplinary counselling programmes, an attempt is made to enable elderly patients to continue to function at the highest possible level, in consideration of their remaining faculties. To do so, different strategies are employed simultaneously and by different medical disciplines: *ADL training and the stimulation of movement* whereby the aim is to maintain the greatest possible degree of independence on the part of the patient in his everyday activities. By offering the same basic information on a regular basis (reality and orientation training), the idea is to sustain the remaining faculties. Providing supporting tools (diaries, orientation inside the patient's own home, walking aids, expedients for household duties, home automation if advisable, etc.) can also bolster self-sufficiency and prove helpful. In addition, the promotion of social contacts is advisable. Alongside support for the person with dementia, these programmes also provide appropriate support for the family carer in terms of his/her understanding of and dealing with persons affected by dementia.

The basis for the counselling of elderly people with dementia is an in-depth understanding of the issues relating to elderly patients and the clinical picture. One should not neglect the fact that each person with dementia is different and requires a tailored approach. In contacts with people with dementia, a number of focus areas stand out, such as physical contact, the need to communicate, the restoration of decorum, patience, respecting territory and privacy and attentiveness to physical health and grooming. It is important that we learn to refrain from pointing out mistakes to a person with dementia and try and make as few changes possible to the patient's living environment, as change makes for insecurity. It is important to keep the elderly person active and to get him to do the things he is capable of himself as much as possible, instead of doing everything for him, all the more so as an elderly person with dementia is not a child.

To the family, an elderly person with dementia revolves around losing someone which goes hand in hand with an entire process: at the outset, there are often feelings of denial of the situation which the person with incipient dementia is affected by, followed by feelings of depression, feelings of guilt, of aggression and ultimately acceptance. The way the nearest and dearest experience the entire situation often fails to be recognised by the wider circle of family, friends and acquaintances as the partner is still present.

In short, in their counselling of people with dementia, counsellors set out on a creative search for expedients for elderly patients and their family carers with the aim of maintaining care in the family setting for as long as possible.

III. Legal considerations

As stated earlier, the present opinion is confined to wandering detection systems that enable people with incipient dementia to continue to take part in their familiar social setting as widely as possible on a self-reliant basis. We do not dilate on wandering detection that is part of a system that is aimed at confining the freedom of movement. As discussed, the constraint of the freedom of movement in a care context is part of an issue that transcends the use of wandering detection.

The issue of the legitimacy and consequently of the permissibility of the use of facilities to track and trace people with dementia who get lost or who have absconded, in law leads to a reflection in accordance with two guideposts which perforce mutually overlap as they both touch upon the respect for the integrity of the person.

The first guidepost is concerned with the respect for privacy, the second guidepost with the acceptance of representation mechanisms to grant permission for acts that are in breach of this privacy.

III.1. Applicable texts

Among the many applicable legal texts, we retain:

- article 8 of the European Convention on Human Rights which guarantees the right to respect for private and family life;
- articles 7 (respect for privacy) and 21 (non-discrimination principle) of the Charter of Fundamental Rights of the European Union of 12 December 2007, as well as - more specifically - articles 25 and 26. Article 25 recognises the right of the elderly to lead a life of dignity and independence and to participate in social and cultural life, whereas article 26 recognises the right of persons with disabilities to benefit from measures designed to ensure their independence, their social and occupational integration and their participation in the life of the community;
- the UN Convention of 13 December 2006 on the rights of people with disabilities, ratified by Belgium in July 2009. This convention recognises the right of persons with a physical, mental, intellectual or sensory disability not to be subjected to arbitrary or unlawful interference with their privacy (article 22), the right to attain and maintain maximum independence (article 26) and the right to move and travel freely (article 18). Article 26, 3, of this Convention specifies: "*The States Parties shall promote the availability, knowledge and the use of assistive devices and technologies, designed for persons with disabilities as they relate to habilitation and rehabilitation.*";
- article 22 of the Constitution, which specifies that: "*Everybody is entitled to respect for*

his privacy and his family life, except in the cases and subject to the terms and conditions laid down by law...";

- the Act of 22 August 2002 on patient rights, with reference to the issue of patient consent;
- the Act of 13 March 2013 reforming the regulations on incompetency and instituting a new protection status that reflects human dignity[15].

The concept of privacy is evolving. Its substance has considerably broadened through the input of the interpretations chiefly returned by the European Court of Human Rights and the Belgian Constitutional Court.

The right to privacy – the very condition to exercise all and any democratic freedoms – today means a right to seclusion, i.e. to intimacy, and a right to independence, i.e. the construction of one's own identity, whereby these rights are protected against the investigations by the authorities, but equally against the infringements by third parties[16].

All texts that guarantee the right to the respect for privacy underscore that this right cannot be absolute and that it is subject to limitations that are justified by the respect for the rights of others or by the general interest. This rule is clarified by article 8, par. 2 of the European Convention on Human Rights:

"There shall be no interference by a public authority with the exercise of this right, except such as in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals or for the protection of the rights and freedoms of others."

The same reservation is also seen in article 22 of the Constitution which specifies that: "everyone is entitled to respect for his privacy and his family life, *except in the cases and subject to the terms and conditions laid down by law*".

Which means that interference is permitted if it meets the criteria of legitimacy – notably for the protection of health –, legality[17], necessity, proportionality and subsidiarity.

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[15] B.O.J. 14 June 2013, 2nd ed., iw 1/6/2014 (see art. 233). T. De Lahaye and F. Hachez, JT2013, p.465; opinion no. 50 of 9 May 2011 of the Committee, published at: www.health.belgium.be/bioeth, 'Opinions' section, under the special Item 3.B. (p. 33 et seq.), which underscores the obligation to involve incompetent persons in the medical decision.

[16] P. Waschmann, 'Le droit au secret de la vie privée', in *Le droit au respect de la vie privée au sens de la Convention européenne des droits de l'homme*, under the direction of F. Sudre, coll. Droit et justice, no. 63, Brussels, Bruylant, 2006, p. 119; B. Docquir, *Le droit à la vie privée*, Brussels, Larcier, 2008, p. 289; B. Docquir, 'Le droit à la vie privée: aperçu général et règle de proportionnalité', in *Actualités du droit de la vie privée*, UB³, Brussels, Bruylant, 2008, p. 1; E.C.H.R., 16 December 1992, NIMETZ / Germany; 29 April 2002, PRETTY / United Kingdom and 16 June 2005, STORCK / Germany.

[17] The reference to the concept of 'law' is to be understood within the formal meaning of article 22 of the Constitution, whereas according to the European Convention on Human Rights interference may be permitted if it rests on an unwritten, for instance jurisprudential rule. But in such cases too, the interference needs to be described in a way that is sufficiently clear; B. Docquir, 'Le droit à la vie privée: aperçu général et règle de proportionnalité', *op. cit.*, p. 24, E.C.H.R., 04 May 2000, ROTAROU/ Romania and 26 October 2000, HASSAN and TCHAOUK/ Bulgaria.

III.2. The criterion of necessity and legitimacy

In appraising the necessity, the interests that prevail need to be weighed against each other. This is a "*conventional*" formula in the rulings returned by the European Court of Human Rights and the Constitutional Court. By way of an example, below is the statement of grounds (B.7) included in the ruling returned by the Constitutional Court on 3 February 2011:

"The legislator, when devising a statutory system which involves interference by the authorities in (someone's) privacy, has a margin of discretion in order to take into consideration the right balance that needs to be upheld between the concurrent interests of the individual and of society as a whole[18]*.*
This margin of discretion on the part of the legislator is not unlimited however: in order to appraise whether a statutory rule is compatible with the right to respect for privacy, it should be established whether the legislator struck the right balance between all rights and interests concerned. To do so, it is not enough for the legislator to maintain a balance between the concurrent interests of the individual and society as a whole, he should also maintain the right balance between the conflicting interests of the persons concerned[19]*, on pain of putting in place a measure which would not be in proportion to the intended legitimate aims pursued*".

The legitimacy and therefore the permissibility of the interference in a person's privacy rests on the endeavour to strike a balance:

- between the private interests and the interests of society;
- between the sometimes conflicting private interests of the persons concerned.

This legitimacy also rests on the introduction of verification procedures that make it possible to ensure the establishment and the preservation of this balance.
In national and international case law, it appears that people's privacy is increasingly in need of being protected, not only by basic rules but also by procedural rules that constitute the necessary supplement thereto[20]. A typical example of this situation is the Act of 26 June 1990 on the protection of the mentally ill in which forcible treatment as part of a sectioning is embedded with basic guarantees and with procedural guarantees[21].

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[18] E.C.H.R., 26 May 1994, KEEGAN/Ireland, § 49, 27 October 1994; KROON et al./The Netherlands, § 31; 02 June 2005, ZNAMENSKAYA/Russia § 28; 24 November 2005, SHOFMAN/Russia, § 34.

[19] E.C.H.R., 06 July 2010, BACKLUND/Finland, § 46.

[20] E.C.H.R., 16 July 2002, P.C.S./United Kingdom.

[21] RCB, Opinion no. 21 of 10 March 2003 on forcible treatment in case of sectioning, available to be consulted at: http://www.health.belgium.be/bioeth, *'Opinions' section.*

III.3. Principles of proportionality and subsidiarity

The principle of proportionality means that the measure that constitutes an infringement of privacy needs to be reasonably justified by the intended purpose, needs to be relevant to serve this purpose and must remain within the boundaries that are necessary to accomplish this purpose[22].

In this respect, a measure cannot be proportionate if other measures exist that are just as efficient but less invasive[23].

This proportionality requirement has elements in common with another concept, i.e. that of subsidiarity, a principle which is brought to mind in a ruling handed down by the European Court of Human Rights[24] on 3 October 2011.

This ruling related to two persons suffering from mental disorders, who were divested of their legal competence. The Court ruled this was an infringement of article 6 of the European Convention in terms of the procedural requirements as these persons had not actually been notified of the procedure, had not been invited to attend the court hearing and had not appeared before the judge. The Court also established an infringement of article 8 as far as the merits of the case were concerned due to the failure to respect their privacy through the infringement of the proportionality and subsidiarity rules. Legal competence may be repealed only after less radical solutions have been considered.

The Court specified that it is legitimate to offer protection to the sick, the elderly or persons who are unable to fend for themselves, but divesting them from their competence is an entirely different matter.

The divestment of competence is a measure that needs to be set aside for exceptional situations and other options must be considered before deciding to put in place such an extreme measure.

The same idea is seen in the European Social Charter of the Council of Europe where article 23 reminds the Member States that they are under obligation to allow the elderly and/or persons with disabilities to remain fully-fledged members of society for as long as possible, that is to say to be able to lead decent lives with the help of the authorities and to take part in public, social and cultural life.

These persons must be able to freely choose their lifestyle for themselves and lead an independent existence in their customary environment, for as long as this is possible.

It is consequently for the State to take affirmative action to make homes available to them that are adapted to their needs and their state of health, or provide the required help to adapt these

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[22] B. Docquir, ‘Le droit à la vie privée: aperçu général et règle de proportionnalité’, *op. cit.*, p. 27.

[23] S. Van Drooghenbroeck, ‘Conflits entre droits fondamentaux, pondération des intérêts: fausses pistes et vrais problèmes’, in *Les droits de la personnalité*, Acts of the 10th colloquium of the *Famille et droit* association, Louvain-la-Neuve, 30 November 2007, Brussels, Bruylant, 2009, p. 299.

[24] E.C.H.R., 3 October 2011, X and Y/Croatia.

homes.
The persons living in an institution must be allowed to be involved in determining the living conditions at the institution.

III.4. Application of these principles in the new Act of 17 March 2013 reforming the regulations on incompetency and instituting a new protection status that reflects human dignity[25]

The Act of 17 March 2013 reforming the regulations on incompetency and instituting a new protection status that reflects human dignity (B.O.J. 14 June 2013), which is set to take effect on 1 June 2014, confirms the general principles defined above and which must be reckoned with in appraising the legitimacy and the legality of wandering detection systems.

The cardinal points are:

1) The principle of proportionality, which means that - given the diversity of the disorders that prejudice affected persons' competence - one needs to strike a balance for each individual case separately.
2) The principle of subsidiarity, which implies that one should seek out the least invasive solution, with the greatest respect for the self-reliance of the person.

The application of these principles comes with the following consequences:

1) The precedence of extrajudicial protection over judicial protection: priority must be given to the actions of the mandatary chosen by the vulnerable person when he still had all his faculties, over the actions of the mandatary appointed by the judiciary.
2) The observance of the general rule of competence which constitutes common law, as the incompetency is the exception.
3) The greater involvement of the vulnerable person in the decision-making process, depending on his faculties: the vulnerable person is to be informed of the decisions to be taken in respect of his person and, insofar as possible, must be given the opportunity to put forward his opinion, which must be taken into consideration, in consideration of his faculties of comprehension.
4) The upgrading of the role of the trusted person. The trusted person is the person who acts as a mediator between the curator and the protected person, who conveys the protected person's opinion if he himself is incapable thereof or supports him in expressing his opinion if he is unable to do so independently, and who exercises supervision of the smooth running of the curatorship. He is appointed by the protected person – with a

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[25] See footnote no. 14.

prior procedure, if possible, for the statement of preference – or by the Justice of the Peace.

The trusted person does not represent the protected person – he neither acts as a mandatary or as a curator. Instead, he holds a pivotal accompanying role that is aimed at ensuring respect for the self-reliance and the will of the protected person.

III.5. Application of these principles to the permissibility of the facilities against wandering

If facilities against wandering are commissioned, various requirements must be met so as to take account of the principles set out above.

1) Respect for the proportionality and subsidiarity principles which means that this usage is to be reserved for the cases where such usage imposes itself in the interests of the persons affected by a mental illness, namely when the absence of a facility against wandering prejudices the person, for instance because it limits his independent mobility or because it harms his health, and not exclusively in the interests of those around him.

2) When regulations permit the use of facilities against wandering for the protection of vulnerable persons, these regulations also need to provide for verification mechanisms that comply with the procedural requirements.

These requirements demands that the decision-making process observed gives all parties concerned a reasonable and fair chance to put forward their position[26] and in particular that the requirements set out below are duly checked:

- respect for the rights, the will and the preferences of the person concerned;
- absence of all and any abuse of influence;
- guarantees of proportionate measures that are adapted to the situation of the person concerned;
- limitation in time of the measures or organised revisability;
- verification at regular intervals by a qualified, independent and impartial body or by a judicial authority.

In other words, the vulnerable person may not be excluded from the decision-making process, and the periods of lucidity must be imperatively utilised and respected.

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[26] E.C.H.R., 5 December 2002, HOPPE/Germany and 26 February 2004, GORGOULU/Germany.

From the above it follows that the verification mechanism not only should be applied to the decision that would be taken to use a facility, but equally for the follow-up process. After all, the vulnerable person is to be involved in the decision, insofar as possible, and his incompetency to consent due to his confused state and his loss of independence need to be assessed at regular intervals so as to factor in prospective periods of lucidity.

Readers are reminded that, in its opinion no. 21 of 10 March 2003 on forcible treatment in case of sectioning, the Advisory Committee on Bioethics pointed out that the consent – in this case for the treatment - "*does not [confine] itself to the decision itself whereby the patient agrees to start the treatment; this consent is sooner to be considered as a factor that constantly applies structure to the relationship between the patient, the nursing staff and the healthcare institution ... as such, it is understandable that we are dealing with an ethical problem if there is no consent because the structure of the normal physician/patient relationship vanishes and this relationship lapses to become a unilateral relationship* ... "[27].

The contrariety between the necessary recourse to coercion and respect for the self-reliance therefore requires that "*the physician verifies the patient's capacity to make decisions (for himself) and asks the latter to give his informed consent, as he would do with any other patient ... the physician shall impose the treatment only in the event of duly demonstrated incompetency ... ultimately, the competence to make decisions is not a static or monolithic element that either exists or does not exist, but a dynamic element which fluctuates over time ... it is for the physician to take this into consideration and to ask the patient for his informed consent to planning further treatment*"[28].

These principles can also be applied in the elaboration of statutory regulations on facilities against wandering.

3) Clear provisions must be devised to establish the conditions for the representation of the vulnerable person who is incompetent to give his consent himself.

If the demented person is no longer competent to give his consent, due care must be taken to make sure the decisions are taken in a sense that is as close as possible in keeping with what the vulnerable person would have wanted had he been competent to express his personal will, with respect for his personal interests and in pursuing to strike a balance between this wish and the need for protection.

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[27] RCB, Opinion no. 21, *op. cit.*, Part II, in particular: item 2.2.1. (p. 5 of the opinion).

[28] RCB, Opinion no. 21, *op. cit.*, Part IV, in particular: item 2 (p. 17 of the opinion).

The stake around which the representation of the person with dementia revolves is to keep, insofar as possible, the person with dementia in a reasonable relationship with others, in order to ensure the actual exercise of his rights, and to maintain a degree of self-reliance, as a possible way of having an influence on those around him in a duly individual way. "Relationship" is understood to describe two-way communication: an "expressive" direction (expression of his will, of his own identity) and a "receptive" direction (comprehension and processing of the message of others). "Reasonable" means that the use, in any way whatsoever, of sufficient own cognitive capacities may not be excluded if one means to maintain a balanced, harmonious or even just simply viable relationship. If the person with dementia faces shortcomings in his expressive, receptive and cognitive abilities, supplementary mechanisms must be introduced that consist of the appointment of a person who is capable of exercising these abilities in the place and stead of the person who no longer has these abilities. As such, these mechanisms are to serve three functions:

1. insofar as possible, to ensure the expression of the will and the own identity of the person with dementia; this role requires that the appointed person knows the person with dementia well and has his trust;

2. to see to it that the person with dementia, in his own interests, properly registers the messages of others (for instance, consenting to a medical treatment, a wandering detection system, appropriate organisation of his everyday life, etc.). This role requires both a certain affective and physical proximity (preferably of a person who lives under the same roof as the person with dementia), to enable that appointed person to fill the assistance function, as well as for that person to have the trust of the person with dementia. The appointed person should be someone who is able to receive and process a message on behalf of the person with dementia, also in the eyes of third parties, to enable him to also have their trust;

3. to ensure the representation of the demented person in a legal sense. Even more so than great trust, this role requires considerable integrity on the part of the legal representative and particular alertness to potential conflicts of interests, amongst other things in respect of the estate. In light of the circumstances, it is quite common for someone from outside the family circle to be the preferred choice.

In this respect, inspiration may be drawn from the representation system which was introduced by the Act of 22 August 2002 on patient rights and by the aforesaid Act of 17 March 2013 reforming the regulations on incompetency and instituting a new protection status, which is set to take effect on 1 June 2014.

The cardinal points are:

1) The preference that is given to the mandatary chosen by the vulnerable person when he was compos mentis to give his personal consent on a self-reliant basis, as this authorisation continues to apply if the principal were to lose his competence to consent.
2) Failing a mandatary, the curator appointed for the protection of the person – who may have been appointed by the person himself, involving a prior statement – who, with the authorisation from the Justice of the Peace, acts to apply a measure to counteract absconding behaviour.
3) Failing a curator, the immediate family members acting in stepped fashion: live-in husband/wife, legally cohabiting partner, common law partner, legal age child, parent, legal age brother or sister, professional practitioner... (this system was already provided for under the 2002 Act on patient rights).
4) Finally, in all cases the actions of a representative who takes the decision, must be supplemented by those of the trusted person – who may also be appointed by way of a prior statement –, who has an accompanying role and who verifies the respect for the rights of the vulnerable person.

IV. Ethical considerations

The literature[29] and the exchanges in the working group covered various moral issues regarding the use of wandering detection systems. A summary run-down of these issues is provided below. Amongst other things, one particular question asked whether the wandering detection technology that is made available to a relative, a family carer or an on-duty service to monitor the movements of a person with dementia by way of a password-protected website prejudices the *privacy* of the person concerned.[30] Wandering detection technology appears to call up less resistance among professional caregivers than among average citizens, presumably because in residential care the *safety* of people with dementia is considered to be more important than their privacy and their *freedom,* especially in cases where the dementia has reached a fairly advanced stage.[31]

In ethical discussions on wandering detection, another question that is raised is if, and how one can involve the person with dementia in the decision-making process on the use of a wandering detection system, and whether or not someone else can do that for him in his place and stead. In addition, it is not easy to decide which people should be assigned with the task of following up on the person with dementia.

Some detection systems are found to be *stigmatic* and for this reason appear to prejudice the dignity of the person. For this reason, some people are opposed to the use of surveillance systems whereby chips are used, without the consent of the person concerned, that have been integrated into an armband or ankle tag.

Another discussion topic in connection with the use of technological expedients is the effect of the use thereof on the quality of the care delivered. For instance, some people are heard wondering whether technology will contribute to less monitoring of the person with dementia or that people will be less concerned with the reasons why someone has wandering behaviour as the technology restricts the dangers of wandering.

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[29] Cf. for an overview of the ethical discussion points, see L. Robinson, D. Hutchings, L. Corner, F. Beyer, H. Dickinson, A. Vanoli, T. Finch, J. Hughes, C. Ballard, C. May, J. Bond, 'A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use' in *Health Technology Assessment* Vol. 10, (2006), No. 26: conflicting principles and values, p. 31vv. and A.R. Niemeijer, B.J.M. Frederiks, I.I. Riphagen, J. Legemaate, J.A. Eefsting, C.M.P.M. Hertogh, 'Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: an overview of the literature' in *International Psychogeriatrics* Vol. 22 (2010), p. 1129-1142.

[30] Cf. the debate in the United Kingdom: http://alzheimers.org.uk/site/scripts/news_article.php?newsID=239

[31] Robinson *et al.*, *op. cit.*, p. 31.

Another reservations is to do with the fact that it is not easy to get people with dementia to use technological expedients as complex matters that upset familiar actions and their usual routines can make them anxious, peevish and even fractious.

In a nutshell, the topics seen to emerge from the ethical discussion on wandering detection relate to privacy, freedom, safety, self-reliance, stigmatisation, loss of quality care, and the intimidating nature of technology. Further to discussing a number of concepts, we will be reviewing these themes by way of the existing literature.

IV.1. Ethical key concepts

A recent scoping study into the ethical aspects of technological expedients used in the residential care for people with dementia or mental problems found that the ethical issues in numerous contributions are discussed in highly superficial terms, whilst lacking a rigorous analysis of what exactly is meant by ‘privacy’, ‘safety’, ‘dignity’ and suchlike. The absence of a strictly defined terminology makes for quite a few misunderstandings. In a considerable number of contributions, the authors confine themselves to rehashing the same insights over and over again for that matter, always referring to the same contributions.[32] To avoid this type of mistake, we will be defining what we mean by privacy, freedom and safety in this context first, before involving these concepts in the discussion.

IV.1.1. Privacy - The respect for privacy is considered as a fundamental right, equivalent to the principle of individual freedom to which it acts as a supplement. This does not mean to say that respect for privacy concurs with the principle of individual freedom or that the principle becomes irrelevant when the person with dementia is no longer capable of freely and independently deciding on the actions he performs or the behaviours he assumes. All the more so as the *privacy* principle does not just relate to the subjective dimension of the right to privacy, namely the perception which the person concerned may have of this right. Same as the principle of individual freedom, respect for privacy is associated in a way that is more objective with the principle of respect for human dignity: the need for protection of the person (in his freedom, privacy, etc.) is not only measured by the way in which this is experienced by this person, but by a shared conception of the respect which every individual is entitled to and which he is equally bound to muster for others, regardless of his personal views on the matter. This requirement of respect for human dignity, which encapsulates respect for privacy, may not be toned down vis-à-vis a person with dementia because he is no longer the master of his actions.

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[32] Niemeijer *et al., op. cit.,* p. 1138 ; ‘As some of the ethical values such as dignity, privacy, and autonomy have proved difficult to delineate, further ethical research is needed to clarify and/or specify these concepts. To that end, both theoretical and empirical research is needed.’ (*Ibid.,* p. 1139).

In other words, *privacy* is to be respected unconditionally. However, this does not detract from the fact that it may be particularly useful to be aware of what makes *privacy* possible in practice, as a purely principled approach does not immediately provide guidance when freedom and self-determination have become difficult to interpret due to mental disintegration. After all, what does respecting a person's *privacy* and freedom mean if that person has become severely demented? Establishing the principle as such does not give family carers, friends and family a take on what respect for the dignity of a person with dementia implies in practical terms. Which is why, in what follows, we are defining what makes *privacy* possible and what this means to the care of people facing dementia on a practical level.

In our everyday lives the distinction between public and private is seen to play an invasive role. All the more so as this distinction is the bedrock for the way we distinguish things everybody should be able to be aware of or which should be accessible to all, from things that are of concern only to ourselves and our close family and the people we know. We use the ‘public’ concept to refer to infrastructure which no one may be excluded from using (such as roads and public buildings), but 'public' is equally used to refer to shared beliefs and collective emotions that lend shape to what we call ‘public’ opinion.

On the whole, people tend to be well aware of what ‘public opinion’ or ‘one’ thinks in society. People are quite good at gauging how something will be perceived from the public reference perspective in a given entente. In a way this is also necessary because it is only when you know what is expected of you in the public arena that you are able to grasp the common significance of what goes on in the community. The awareness of ‘one’ will perceive something in a given entente,[33] is something we implicitly factor in the way we communicate at all times, because this perspective enables us to gauge how others within the given entente are expected to understand our behaviour, our expressions and our status.[34]

The need for *privacy* has to do with the protection of a person's public identity. If the image people in our community have of us is wrongly distorted in a negative sense, this will harm our public status. Put simply, people want to exercise a degree of control over their public identity and over the way in which they are publically perceived. This is why the distinction between public and private is a profoundly structuring force that rules our behaviour. It makes us distinguish between the way we behave in public and the way in which we behave in our private lives.

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[33] The expression ‘generalized other’ and the line of reasoning adopted in this paragraph were mainly derived from the work of George H. Mead, *Mind, Self, and Society form the Standpoint of a Social Behaviourist*, Chicago, The University of Chicago Press, 1972.

[34] In modern-day society, social control and moral pressure are experienced as impediments. Being aware of what the social entourage expects from you would veer towards conformism. The fact that people take account of the things that are going on in a given entente is the rule however, because behaviours that do not spark interaction are meaningless and vacant and because communication without any awareness of the way one will be understood is impossible. Even people of a highly self-minded disposition, who have a strong personality and are original, as a rule tend to be implicitly aware of the kind of figure they cut, well wise to the way in which what they say and do comes across, and probably especially when they are out to shock others or adopt non-conformist behaviour.

Easy telltale signs include the way we dress (business suit versus casual wear), the way we speak (formal versus informal language), the kind of views and thoughts we communicate or the kind of humour we cultivate. Our need for *privacy* is structured by our wish to hide engaging in intimate behaviours (for instance when we are intensely sad or when we are hugging someone) or behaviours that are considered to be embarrassing (for instance when going to the toilet or when vomiting) from the outside world to protect our public identity. Without the option to withdraw into our personal privacy, it is difficult to maintain decorum and public dignity. If our intimate behaviours were permanently visible to public scrutiny, they could be seized upon by strangers to harm our image. For the reason that people need to be able to protect their honour and their good reputation, people have the right to conceal what goes on in their private lives or their strictly personal experiences from the public world, except in the event of reprehensible actions.

In addition, the right to *privacy* is often associated with the right of individual citizens to shirk the control exerted by fellow citizens and authorities. In this context, *privacy* is contrasted with *big brother* situations whereby our private lives are charted by outside parties through the use of technological expedients with a view to wielding power over us.

Technology that makes it impossible to conceal our private affairs is felt to be a threat to our *privacy*. The idea that - when wearing a ‘tracking device’ for instance - we are no longer able to hide from others when we are outdoors, or the idea that there is nothing we can do that will remain unseen because we are constantly being watched by a camera, is something we consider to be offensive. After all, this type of technology compromises our control over our public status.

The public-private distinction is one of the crucial categories on the basis of which people structure their behaviour. Same as the distinctions we make in consideration of time and space or in consideration of what is real, probable or fictitious, the public-private distinction acts as a framework that lends order and structure, on the basis of which we are able to meaningfully interpret what we or what others do.

Because these kinds of cognitive categories are seen to disintegrate over the course of the dementia process, the public-private distinction for people in an advanced stage of dementia loses all meaning. They become oblivious to whether their behaviours in public are considered as appropriate or inappropriate, which is why they stop making any attempts at concealing that behaviour from the gaze of strangers. They stop looking after themselves, leave their intimate parts uncovered, and suchlike. They lose their decorum.

Yet, *privacy* remains important, even in the advanced stages of dementia. Family, friends and carers who look after the person in question will consider it their duty to protect the decorum of that person out of respect. This means they will mask over things that might prove detrimental to the public dignity of the person with dementia and lend prominence to things that are beneficial to that person's public identity. For instance, they will prevent strangers who do not belong to the private circle, from getting a look-in - for non-professional reasons - on the conditions that prejudice the image of that person. This type of care is an expression of love and a sign of respect for the person who is no longer there due to cognitive impairment. Even if, from a purely utilitarian context, this is something people are often oblivious to, this type of care remains crucial.

IV.1.2. Safety – The 'safety' of people with dementia with wandering behaviour first and foremost stands in reference to the prevention of physical harm. People who are confused and disoriented and start wandering could get themselves killed in traffic, lose their way and end up suffering from hypothermia in dire weather conditions, have a fall or end up in trouble for failing to take their medication. Wandering detection systems can help prevent this. However, safety can also be seen in a wider perspective. People not only feel threatened when the risk of physical harm increases as a result of chance circumstances or the deliberate actions of others. People can also feel unsafe when others threaten to belittle, disparage or bully them. Alongside the threat to a person's physical integrity, psychological terror too can jeopardise the safety of people, involving humiliations or hurtful reproaches for instance. Sadly, the fear that is engendered in case of psychological terror is difficult to register and consequently often goes neglected.

It is not exactly clear how significant the physical safety problem experienced by people with dementia is. Figures produced by the Missing Persons Cell (Federal Police) show that in 2011, 148 cases of people with Alzheimer's were opened, i.e. 9% of the total number of missing person cases. 143 persons were recovered alive, which means 3.3% failed to survive their undertaking.

Wandering detection technology is able to mitigate this problem by helping to prevent people from leaving their residence. In those instances, the technology is committed within the context of restraining a person's freedom of movement. As indicated, this aspect is left unaddressed in the present opinion as it is part of a more comprehensive issue. However, wandering detection technology may also be committed to enable persons with incipient dementia to go outdoors. In those cases, the safety element lies in the fact that, when the individual remains out for a protracted length of time or gives a sign himself, it is comparatively easy to get him home safely.

In residential care, priority often goes out to physical safety because of the legal liability that applies if the physical integrity of the persons entrusted to the care and supervision of the residential facility is prejudiced. The authors of studies on technological expedients for people with dementia and their family carers equally consider the physical safety aspects and the comfort of the caregivers more important than elements such as *privacy* and self-determination.[35] The reason is probably that in their studies, they are only working from information supplied by caregivers and the fact that they are unable to allow people with dementia to speak much for themselves.

IV.1.3. Self-reliance- In ethical discussions about the care of people with dementia, marking out the boundaries of the concept of 'self-reliance' is probably the most crucial thing, because ‘self-reliance’ is used both in the arguments for and in the arguments against wandering detection technology, albeit on the basis of two different concept interpretations.

Strictly speaking, self-reliance is defined as ‘self-determination’: the ability to cognitively weigh up different perspectives, expectations and intentions and, on the basis thereof, to arrive at decisions for oneself, independently from others. Self-determination is considered as an important value because it is believed to be the cornerstone of an individual's personality. It is precisely because someone is capable of self-reliantly determining how to organise his life that a person is perceived as an individual personality. As a result of the strict definition of self-reliance, it is true to say that when the cognitive ability to independently arrive at decisions starts to disintegrate, as is the case for people with dementia, showing respect for self-reliance gradually becomes irrelevant.

There are good reasons to adopt a broad-based rather than a strict definition of self-reliance. Decisions that are made wholly independently are relatively rare. In practice, the things people decide on are usually the subject of a person's personal choice as well as being determined by social or physical factors. Especially as ‘wanting something’ is mostly commensurate with ‘consenting to something’ which already appealed to you beforehand. What we want is often something which already drove us ahead of time, either physically, or because of the social expectancy system we participate in. Whilst the strict definition of self-reliance suggests that we only make self-reliant choices when we were taking decisions entirely by ourselves, independently from others, in practice the thing we want or which we unconditionally want to care for and keep safe, is never the product of what we have chosen in complete isolation from the outside world. All the more so that, if this would be able to be the case, we need to be able to ignore the social significances of the things we opt for. In this respect, the significance of the projects we are committed to are not just determined by ourselves, but equally by the cultural significance system we participate in. The things we choose have a certain relevance and a certain value in the entente we live in, and it would be absurd to ignore this with every independent

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[35] P. Topo, P. ‘Technology studies to meet the needs of people with dementia and their caregivers’ in *Journal of Applied Gerontology,* Vol. 28 (2009), p. 5-37.

decision we make. A broad-based view of self-reliance sees us taking consideration of the fact that none of us are able to arrive at meaningful decisions in complete isolation from our relationships with other people that are the upshot of developments over time. The things we 'independently' want are the things we have to come to consider important through personal experiences, our upbringing and interpersonal contacts over the course of our lives. In determining the things someone stands for, or the things someone wants, there is no need for us to ignore the way in which a person's character has been moulded by his entourage, social relationships, upbringing or culture. The things a person stands for, the things someone really wants are not something this person decides at a single isolated point in time whilst discounting his past or social entourage. The things someone really wants are mostly grafted onto a series of trends which that person consented to over the course of a lifetime in consideration of the social circumstances that made him into what he is today and what he means to be in the future.

For this reason, respecting a person's self-reliance in the broader sense may be construed as respecting his character in the way it has been moulded by social and cultural conditions or as respecting someone's private wishes and habits that were moulded as part of his specific web of interpersonal relationships. Setting out from this broad interpretation of self-reliance, it remains meaningful to aver that the self-reliance of people in the process of dementing should be respected. Even if a person is no longer cognitively capable of making clear-cut decisions himself, those close to him still know what is important to him. As a result, they are usually confident they know what he ‘wants’. In advanced dementia, this attachment is seen to disintegrate with all signs of individuality fading away. Yet, close friends and family members can continue to grasp what the person in question would have wanted in these situations.[36] In the literature, someone who - further to a close association and identification with someone's character - is able to make out what the person in question would have wanted is referred to as someone's ‘proxy appear’. It is felt that this type of person may be consulted when important decisions need to be made which the person with dementia is no longer capable of making himself. This person is not necessarily someone's legal representative or the family carer. Ideally, the family carer or a close relative who assumes responsibility for the person with dementia should also be able to serve as a ‘proxy appear’. In these circumstances, it is important that when someone is appointed as the representative, this is someone who not only protects the rights but also the self-reliance of the person with dementia.

By the same token, the broad interpretation of self-reliance is seen to shed light on another

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[36] The physical appearance of a person in the advanced stages of dementia, is experienced by the people close to him as a symbol of the person that was, a symbol for which relatives, friends and acquaintances are able to muster respect and devotion from a human perspective.

crucial aspect of the care of people with dementia. Because the things someone stands for are given substance through the network of social relationships in which he is embedded, showing respect for the self-reliance of the person concerned also implies ensuring his social citizenship for as long as possible.

When people are admitted into hospital, they are made to find that their social status means very little, if anything. The patient is asked to undress and is divested of the significance he holds within his familiar social, professional, civil or family context. Viewed from the angle of the care system, an individual in a sick bed is an isolated physiological organism with a dysfunction. This disregard in this type of setting is pragmatic and necessary, but when an disorder is chronic in nature and the care institution becomes the patient's new permanent residence, the disregard of social and family relationships goes hand in hand with the reduction of that person's identity, and accordingly with a lack of respect for that person's self-reliance.

Showing respect for the self-reliance of the person in the wider sense, does not mean that account is solely taken of what that person independently decides for himself at that point in time. It means that measures are put in place that cater for his habits and routines. It implies that he is enabled to maintain familiar relations with his own possessions, his own family, his own social entourage, his own social life. As time moves on, taking part in social life is no longer an option for people with dementia. However, this does not mean to say one cannot continue to respect the self-worth of people in the advanced stages of dementia, for example by continuing to smartly dress or nicely make up someone who has always taken pride in his or her appearance, etc.

Wandering detection technology can be committed in the initial stages of the dementia process to enable the individual to continue his ‘normal’ life and to step outdoors because it allows him to go out without being in fear of getting into trouble because he knows that he can be monitored and assisted to find his way by someone he trusts.

For those who interpret self-reliance in the strict sense, wandering detection technology is likely to be problematic because the family carer's patronising nannying seems to stand in the way of self-determination. Strictly speaking this is true. In this respect, it is important to establish who will decide on the use of the wandering detection system and who can closely monitor the person with dementia when he steps outside using the system. At the same time, it is true to say that the use of wandering detection technology in the initial stages of the dementia process expands the self-reliance in the broad sense of the person with dementia. All the more so as this enables him to self-reliantly continue his habits and routines for longer, visiting friends away from home, going for a drink or going shopping. In the early or moderate stages of dementia, the self-reliance of the patient in the broad sense is imperilled when he is divested of his lynchpin function in a network of relationships and he is admitted into an alien environment where he is made to lose his social and family status.

IV.1.4. Freedom and restraint

As previously indicated, the present opinion deliberately disregards the use of wandering detection within the context of a system that restrains the freedom of movement. Instead, we confine ourselves to the finding that constraining someone's freedom of movement raises a great deal of questions, not just from a legal perspective but equally in a moral sense. A scoping study on non-pharmacological interventions to counteract wandering behaviour shows that restraint is considered to be morally irresponsible, but that there are circumstances where no other solutions are available.[37] In this context too, the mental capacity of the person whose freedom of movement one is seeking to restrain makes all the difference. It goes without saying constraining someone who still has a lot of lucid moments and who is greatly aware of his situation is different in nature than confining the freedom of movement of someone who is in the advanced stages of dementia. However, the problem with constraining someone's freedom of movement as part of care is a topic that transcends the implementation of wandering detection technology. The point being that wandering detection is just one of the wide array of resources and expedients used in the care sector to constrain people's freedom of movement. To discuss the issue with any degree of accuracy, all of these resources would need to be reviewed together, which cannot be the whole idea within the confines of the present opinion.

IV.1.5. Respect for the uniqueness and dignity of the person – In the foregoing description, we already took a sideways look at what respect for the uniqueness of the person with dementia can mean. In line with Kitwood and the social scientists who advocate the importance of social citizenship, respect for the uniqueness of a person with dementia implies positively no disregard of the patient's social, social and family interconnectedness. Especially as a person's dignity is linked to the way in which his entourage perceives him as part of a community which he derives his status from. Family and family carers can underpin and assume the protection of that dignity by identifying with the things the patient would have wanted for himself, even if his ability to express his own will has greatly disintegrated.

There are acute reasons to remain keenly aware of the need, in the context of care for people with dementia, same as for the elderly in general, to show respect for the dignity of the human person. People find that their mental and physical abilities are gradually deteriorating, often

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[37] Robinson, *et al.*, *op. cit.,* ‘Physical restraints were felt to constitute an abuse of civil liberties, although the intent or purpose of the restraint was felt to be an important mitigating factor in their use.”

feeling as though they are a burden on everyone because they are frail and in need of care. They find it difficult to feel they still mean something and realise that they are no longer in a position to contribute to the well-being of those around them. The accepted economic discourse on the future of society views chronic care recipients as a threat because - in keeping with the ageing of the population - their rising numbers are set to exponentially drive up the cost of care and healthcare which will put the wherewithal of our society to the test. As it is becoming increasingly more difficult for people who need long-term care in this type of entente to live by the grace of the thought that they are valuable, more so than young people, they find themselves asking: 'What is the point of living'. If, in a residential setting, the status and dignity of the individual are being erased for pragmatic reasons and every resident is considered a number whose physical integrity needs to be protected before all else by monitoring people's diets, hygiene, medication and physical exercise, this only serves to confirm the unsettling concerns of these care recipients. In order to allow the particular identity of people to be appreciated and to show them the respect that gives them the courage to go on living, it is important that people continue to remain part of social and family-based networks or are enabled to live in a setting where they can make a difference for as long as possible. In this respect, the choice put forward as part of the Dementia Plan to support and care for people with dementia in their home environment for as long as possible is duly justified.

IV.2. Ethical trade-offs

IV.2.1. Ethical trade-offs differ in consideration of the development of the dementia process

Obviously the nature of the trade-off that will need to be made in the implementation of wandering detection technology will vary in consideration of the faculties the person with dementia has and of the financial resources of his entourage. For this reason, we are making a distinction in this paragraph between people who were only recently diagnosed with dementia and who are only confused and disoriented episodically, and people whose self-conscious has been severely affected by the dementia process.

IV.2.2. Privacy and freedom versus safety and stress relief for the family carer

When people with dementia still have a lot of lucid moments during which they are aware of their situation, it is usual for them to place importance on being able to continue their normal lives for as long as possible, to maintain their familiar social relationships as widely as possible and to conceal their personal privacy from the scrutiny of strangers. During this stage, it is not immediately opportune to resort to wandering detection systems to prevent the person with dementia from leaving his own home. In this stage, round-the-clock camera surveillance is a severe infringement of *privacy*. As the dementia process progresses however, safety will come to gradually override *privacy* and freedom as the latter becomes less relevant to the person concerned due to the impairment of his cognitive faculties. The difficulty is to make the right choices in the intervening stages. In an ideal situation, the family carer, the care recipient and the care team are able to decide together what would best be used. 'Ideal situation' - as suggested in the Dementia Plan -, refers to the situation in which a timely diagnosis of dementia is delivered and the ability to cope of the person with dementia and his family carer is supported, for instance by a professional who acts as the primary contact. This would see the latter attend to all practical and administrative matters required for the medical, psychosocial and legal procedures, and oversee the multidisciplinary care concertation[38].

As to the threat to *privacy*, the trust placed by the patient in the person in charge of the wandering detection system is crucial.

Insofar as the person who monitors the person with dementia is someone who is part of the circle of people who make up the patient's private world or someone whom the person with dementia trusts, the risk of the patient's own privacy being compromised will not be seen as problematic. If the mutual trust between partners or family members has broken down and the atmosphere in the home environment has become sour or even hostile, this will be less straightforward. These kinds of circumstances need to be taken into account as part of care concertation.

In residential care, professional caregivers will be quicker to allow the physical safety of the person to take precedence over the freedom and *privacy* of the care recipient. This is to do with the liability that rests on professional care workers but equally with the atmosphere and rapport that exists in a residential institution. If financial strictures, administrative over-regulation and staff shortages compel management to commit staff as efficiently as possible, there is little chance of the welfare of the care recipient taking first place when technological expedients are used. As illustrated by the use of psychopharmaceutical drugs in facilities for the care of the elderly, technological expedients will be used in residential institutions in order to ensure the material welfare of patients with as little human resources as possible, whilst all non-administratively verifiable care aspects (human contact, mental safety, privacy, understanding and attention) will go ignored.

IV.2.3. Self-reliance versus nannying

As indicated, in the discussion on the use of wandering detection technology questions are raised as to the patient's self-reliance in a range of different respects. To protect the right to self-reliance in the strict sense, the individual must be enable to decided on the application of

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[38] This professional is referred to as the "dementia consultant" in the "2010-2014 Flanders Dementia Plan".

the system himself. In addition, it is assumed that the system itself, once it is being used, may result in nannying. It might well prompt family carers, family members or social workers to adopt a patronising and controlling approach.

In the initial stages of the dementia process, the matter is obviously different in nature than in the later stages. In the initial stages, the commitment of wandering detection technology largely involves the use of GPS systems that enable a person's movements to be monitored. At later stages, these mainly involve surveillance systems. The obvious thing to do is to involve the person with dementia in the decision-making process on the use of the system. The patient's consent would seem to be an imperative requirement. However, numerous studies show that the ability of people with dementia to make clear decisions is not always unequivocal. In practice, the decisions are often taken by the family carers who are closest to the person with dementia and who are able to act as 'a proxy appear'. Usually this is the partner.[39]

Family carers turn out to be somewhat distrustful of professional care workers as they suspect the latter are insufficiently familiar with the difficulties involved in concrete cases. Professional care workers are more often seen to set out from a strict conception of self-reliance. Family members and family carers tend to favour a broad conception of self-reliance, taking the view that the spouse or the family carer is well placed to determine what is in the best interests of the dignity and the specific needs of any specific person. Especially in the stage where the cognitive faculties of the person with dementia start disintegrating, mustering respect for someone's self-reliance means doing justice to what - based on personal familiarity with the patient - you may consider as what the person would have felt to be important for himself. This implies a multidimensional vision of self-reliance.[40]

IV.2.4. Stigmatisation versus respect for the dignity of the person

Wandering detection systems that involve the use of ankle tags or wristbands and systems whereby a chip is implanted are considered stigmatic in our society. Ankle tags are instinctively associated with criminals and the implantation of chips with livestock farming. From a purely efficiency-led perspective, people are likely to be inclined to overlook these negative symbolical tenors, but because of the required respect for the dignity of the human person, this is not ethically responsible.

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[39] For this concept: see supra 4.1.3.

A study in which elderly people, people responsible for family care, social workers, professional service providers and social work students were asked who they felt should make the decision to introduce GPS wandering detection technology in home care, established the following ranking: the spouse, the carer most closely involved in the home care and the person with dementia himself. The physician, the multidisciplinary team or the social worker were least often designated. C.f. R. Landau, G.K. Auslander, S. Werner, N. Shoval, J. Heinik, J., 'Who should make the decision on the use of GPS for people with dementia?' in *Aging and Mental Health,* Vol. 15 (2011), p. 78-84. Slight differences were found between the groups queried. Family carers appeared to be less easily prepared to relegate the responsibility to the people with dementia themselves, whilst social workers were greater in number to feel that leaving the decision to the multidisciplinary team was the best way forward.

[40] B.A. Elliott, C.E. Gessert, C. Peden-McAlpine, 'Family decision making in advanced dementia: Narrative and ethics. In *Scandinavian Journal of Caring Sciences*, Vol. 23 (2008), pp. 251-258.

Along with a wide number of other institutional practices that are aimed at enhancing efficiency, ankle tags, wristbands or implanted chips can be considered as a denigrating characterisation that marks out a human being in residential care to a 'traceable' object. Applying 'labels' sees us unthinkingly create a distinction between people, and the effects of the division that are produced as a result may have an alienating effect, which may come to symbolise the fact that the particularity of the person is disregarded.

IV.2.5. Wandering detection versus quality of care

The fear that the quality of care will deteriorate as a result of the use of wandering detection aids is especially real in residential care where resources are scarce and staff (unavoidably) needs to be committed as efficiently as possible.

Wandering behaviour in people with dementia is often elicited by specific situations. Gaining insight into the causes, the nature and the consequences of the patient's wandering behaviour produces a better understanding of the person with dementia and enables carers to better anticipate his behaviours.[41] The use of a wandering detection system could prompt carers to dispense with the need to remain attentive to the above, which comes with reduced quality care. Concerns exist over wandering detection systems being put in place in residential settings in times of financial strictures so as to limit the human resources committed to keep an eye on people with dementia, and in doing so cut payroll expenditures, which would jeopardise the quality of care.

In home care too, wandering detection systems may cause family carers to no longer constantly monitor the person with dementia, even though this does not necessarily need to be a bad thing. Family carers have a physically and mentally demanding task. Wandering detection systems can enable them to devote their time to other duties without living in fear of what the person with dementia might be doing.

IV.2.6. Technological advancement versus the preservation of 'the normal run of things'

A wide number of studies and a pilot scheme (E-Tandem Live) show that both the people with dementia and their family carers are wary about technological expedients. Especially when the expedients do not work properly, are too cumbersome or impractical, a lot of people become greatly opposed to technological aids. Whilst engineers are often enthusiastic about the possibilities offered by the technological expedients they are looking to implement, a lot of people take a great deal of convincing to embrace devices whose operation or effectiveness they do not fully understand or trust.

A sweeping development has been unfolding over the last decade. First of all, the GPS wandering detection systems have become much smaller in size and much more user-friendly to boot.

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[41] In this connection, the literature refers to the *ABC approach, i.e. determining the antecedents, behaviour and consequences of wandering* Robinson *et al., op. cit.* , p. 36.

All that is required for the person with dementia is for him to carry a kind of GSM device about his person and for the family carer to be able to use the Internet. A second factor that raises the acceptability of wandering detection technologies, is the fact that the generation of people who are affected by dementia today is duly familiar with GPS devices and the Internet. This trend is here to stay and will go from strength to strength. GPS wandering detection systems in the guise of technological tools that have already been integrated as part of 'the normal run of things' are less intimidating. The outlay for this type of devices is comparatively reasonable. In The Netherlands the purchase of the basic device would currently set the user back € 375.00.[42]

With regard to the element of cost, the potential drawbacks and benefits of a purpose-designed and approved (and consequently presumably expensive) system need to be carefully weighed against the possible use of applications for mobile telephones that are commonly available on the market at reasonable prices. In no event should the cost of a system be allowed to act as a source of discrimination. If necessary, the payment of such a system should be considered by the authorities. In addition, one needs to be alive to the fact that the technological nature of the system in itself can also be a source of discrimination if it requires a certain infrastructure (Internet, mobile phone, etc.) and specific competencies or skills.

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[42] http://www.zorgriem.nl/bestel-de-zorgriem

V. Recommendations: limiting conditions in connection with expedients for wandering detection of people with dementia in home care situations [43]

The following limiting conditions relate to the use of GPS wandering detection technology. This technology is an expedient that may prove useful in the initial stages of the dementia process to enable people with dementia the possibility to go out and do the things they would normally do: shopping, seeing friends, walking the dog, sitting down on a terrace for a drink and suchlike. The device allows the family carer to establish where the person is and help him on his way or have him picked up if he is lost. This system is known in The Netherlands as the 'zorgriem *(care belt)*'. Feedback on the system is still in its initial stages but all in all is positive across the board[44]. In setting out the limiting conditions, we have taken our cue from recent literature[45].

The following recommendations imply an early diagnosis of dementia.

V.1.

Once the diagnosis has been made, it is important to put in place a pluridisciplinary care team as soon as possible that will concert in a duly structured manner, whereby the person with dementia, the family and the caregivers all have a say in deciding on things such as the use of GPS for example.

Ideally, the nearest and dearest of the demented person are to be informed, guided and given administrative support by a primary contact on the steps to be put in place and the procedures to be observed.

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[43] For the purpose of the present opinion, it was decided to use general terms such as "the person with dementia", "the partner" or "the patient" and references to these persons as "he" or "she" in the interests of the legibility of the text. Needless to add these terms relate to both men and women.

[44] See A.M. Pot, B.M. Willemse, S. Horjus, 'A pilot study on the use of tracking technology: Feasablitiy, acceptability, and benefits for people in early stages of dementia and their informal caregivers' in *Aging and Mental Health.* Vol. 16 (2012), No. 1, p. 127-134.

[45] R. Landau, S. Werner, 'Ethical aspects of using GPS for tracking people with dementia: recommendations for practice' in *International Psychogeriatrics*, Vol. 24 (2012) p. 358-366.

V.2.

A distinction should be made between wandering detection technology whose aim is to constrain a person's freedom of movement (by locking down a room/place or by shutting a passage or exit), and wandering detection technology as an expedient to track and trace a person. For home care purposes, only the second application can be considered as it is impossible to exercise supervision over measures aimed at constraining someone's freedom to move around freely, even if this constraint rests on statutory provisions.

V.3.

The decision to adopt wandering detection technology needs to be made after the first diagnosis, by the family carer, the family members and the multidisciplinary care team, together with the person with dementia.

The duty to involve the person with dementia in the decision is fundamental. At no point in time should the patient be forced to use wandering detection systems. If he refuses to co-operate, forgets to activate the expedient or removes the device, he should never be exposed to any kind of sanctions.

If the person with dementia is no longer capable of consenting, due pains must be taken to ensure the decision is made by a person who is duly placed to represent the vulnerable person in the fullest respect for the latter's rights, in application of the rules set out under the Act of 22 August 2002 on patient rights and under the Act of 17 March 2013 reforming the regulations on incompetency, which is set to take effect on 1 June 2014.

Respect for the rights of the vulnerable person and observance of the general principles of proportionality and subsidiarity in particular must be ensured by the actions of the person who is best placed to express what the protected person would have wanted: his mandatary, his curator duly authorised by the Justice of the Peace (Act of 17 March 2013), the immediate family members acting in stepped fashion: live-in husband/wife, legally cohabiting partner, common law partner, legal age child, parent, legal age brother or sister, or finally the professional practitioner who tends to the vulnerable person (this system was already provided for under the 2002 Act on patient rights).

In all cases the trusted person should also act to ensure due respect for the vulnerable person and guide and support the said person in a moral and affective sense.

These acting persons are to be appointed ahead of time by the person to be protected when he was still capable of clearly expressing his wishes.

V.4.

The decision to use an expedient and the choice of the expedient to be committed must be made in observance of the principles of necessity, proportionality and subsidiarity and particularly in consideration of the extent to which the proposed expedient constrains or affects the freedom, privacy and the dignity of the person with dementia.

In deciding on the use of wandering detection systems to monitor people with dementia, it is not just the behaviour and the values of the person with dementia that must be taken into consideration, but equally what is in the best interests of the person with dementia and of the family carers. As such, it is important to perform a meticulous trade-off, weighing up the needs of the person with dementia: his safety, his need for self-reliance and privacy, without omitting the care burden for the relatives.

V.5.

The use of an expedient must be monitored by a pluridisciplinary team in accordance with procedures to be set up so as to ensure due account is taken of the prospective changes in the patient's medical condition that warranted the expedient being put in place, and in accordance with the principles of necessity, proportionality and subsidiarity.

Pains must be taken to make sure that the person with dementia and the relevant persons in his entourage are duly familiar with the wandering detection system used (e.g. by integrating the system in a conventional mobile phone set). Equally, pains must be taken to make sure that the technological aspects of the system do not go on to become a factor of discrimination due to the fact that they require special competencies or skills. The system must be small, easy to carry around and practical to use. The cost too cannot be allowed to act as a source of discrimination, with the authorities urged to consider enabling reimbursement by the social security system if need be.

V.6.

The use of expedients for wandering detection does not exclude other solutions. Reference is made to involving existing track and trace expedients that have been the topic of concertation between families, nursing staff and the police – as is already in place in the HEKLA police region – or other schemes, supported by private or public institutions, provided these solutions comply with the ethical requirements set out above.

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The opinion was prepared in the select commission 2011/2, consisting of:

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Mrs N. Gallus, Member of the Committee

The working documents of the select committee 2011/2 – request, contributions from the members, minutes of the meetings, documents consulted – are stored as annexes 2011/2 at the Committee's documentation centre where they are available to be consulted and copied.

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This opinion is available on the website www.health.belgium.be/bioeth under the heading “opinions”.