

SOLIDARITY IN HEALTHCARE – THE CHALLENGE OF DEMENTIA¹

– Aleksandra Głos –

Abstract. Dementia will soon be ranked as the world’s largest economy. At present, it ranges from the 16th to 18th place, with countries such as Indonesia, the Netherlands, and Turkey. Dementia is not only a financial challenge, but also a philosophical one. It provokes a paradigm shift in the traditional view of healthcare and expands the classic concepts of human personhood and autonomy. A promising response to these challenges is the idea of cooperative solidarity. Cooperative solidarity, contrary to its ‘humanitarian’ version, promotes spontaneous teamwork and individual initiative. It obliges us not only to help ‘the suffering, the troubled and the disadvantaged’, but above all to support those who already do so for spontaneous moral or affective reasons. In the field of dementia study, solidary initiatives are described within the framework of supportive care.

Keywords: solidarity, dementia, supportive care, Ruud Ter Meulen, David Heyd, Julian C. Hughes.

1. Introduction: Dementia and the limits of health care

Dementia can be considered a ‘borderline’ case in healthcare because the care needed by sufferers lies on the border between home care, social care and healthcare, and as such forces the rigid frames of these divergent kinds of care to expand and become testing grounds for their work together. Dementia also exposes the limits of the healthcare system in the most visible manner: its prevalence and gigantic costs have led traditional healthcare to the verge of insolvency, creating an urgent need for a paradigm shift in the theory of care giving, as well as a change in practice. New models of care and a new catalogue of good practices, which could emerge from this crisis, can be described as solidary.

At first glance, this may seem controversial. How can the growing costs of dementia care be an argument in favour of solidarity? It can be rightly argued that the principle of solidarity, as the cornerstone of a welfare state, is precisely the same factor that renders healthcare systems insolvent. In the face of the constant

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ageing of European society, and consequently the growing prevalence of dementia, the administrative obligation to help the sickest, the poorest and most 'needy' will soon turn solidary assistance into a bottomless pit. This, however, refers only to the traditional, welfare-based model of solidarity. But the example of dementia care challenges this model. Dementia care affects not only the financial stability of the healthcare system, but also the traditional models of human personhood and healthcare, thus transforming the very concept of solidarity itself.

This article will be divided into three parts: in the first part, I will explain the threefold challenge posed by the needs of dementia care to traditional healthcare – philosophical, structural, and financial. In the second part, I will present two models of solidarity, humanitarian and cooperative, which give rise to two different models of healthcare. In the third part, I will describe current theoretical and practical changes in dementia care, which illustrate the evolution of solidarity in healthcare from the welfare-based to a more cooperative model.

2. The three challenges of dementia

2.1. The philosophical challenge

The challenge posed by dementia is threefold. The first and most important challenge is philosophical: dementia changes the traditional view of human personhood and autonomy, emphasizing their social dimensions.

Dementia (Latin: *de* from, *mens* mind – 'out of one's mind') describes a number of symptoms, from memory impairment and communication problems, changes in mood and behaviour, to the gradual loss of control of physical functions. It is a complex biological condition resulting from degeneration of the nerve cells, and has psychological and social consequences. Deterioration of cognitive abilities follows progressively, and this process is often divided into three stages. First, there is the early ('mild') stage, where sufferers have memory problems, impaired attention, judgment and awareness, decision-making problems and mood swings, and sometimes aggressive episodes. A sufferer at this stage could be described as being 'out of herself'. In the middle ('moderate') stage, sufferers experience disorientation, easily become lost and expose themselves to risk, and are thus excluded from normal life. In the late ('severe') stage, sufferers lose control of bodily and cognitive functions, cease to recognize their closest relatives and lose the ability to speak – they are then, literally, 'out of their minds'².

Due to this progressive deterioration of cognitive capacities, dementia challenges the traditional concepts of identity and personhood, and therefore human

² Cf. NCoB [2009] p. 4-6.

autonomy. The concept of personhood is based on two cognitive premises: rationality and memory. Rationality is expressed by a man's capacity for logical reasoning and his ability to curb his passions. The traditional model of rationality can be suggestively illustrated by two figures, ancient and contemporary. The ancient one originates from Plato: it is the widely-known figure of 'soul as a chariot', led by horsemen and two jibbers, where the horsemen, obviously, symbolize the rational mind, and the jibbers are passions and emotions. The requirements of rationality are here straightforward: the rational man should always listen to the horsemen (rational commands), and tame the wild horses (passions). This ancient model of rationality is still prevalent in the western culture: the same message is conveyed in contemporary rational choice theory. In this model, the rational man is depicted as Ulysses, who repeats the gesture of the horseman and deafens himself to the call of the sirens.³ It is clear that in these traditional Olympian⁴ ideas, emotions are treated not only as irrational, but even detrimental and destructive. The second premise of personhood is the continuity of memory. The most famous answer to the difficult question of 'What makes it that a person at one time is the same person at a different time?', is that of John Locke. It is not the substance, not the bodily identity, but the continuity of memory, which gives us the sense of self, says the philosopher. Identity can be imagined as auto-narration – a total sum of sentences we can utter about ourselves on the basis of our history, our consciousness and self-knowledge. From this, the traditional concept of autonomy follows: if rationality requires self-control, and identity is constituted by conscious auto-narration, then autonomy cannot be understood as anything else than the ability to make individual, fully-informed and independent decisions.

Rationality and memory are precisely the same capacities that are impaired by dementia. The process of impairment is, however, gradual, expands over time and is never fully predictable. Even in difficult cases, a sufferer can manifest sudden moments of awareness. The loss of cognitive functions cannot be thus treated in a binary, 'zero or one' way. The fact that a person's consciousness can fluctuate or re-emerge requires development of attentive tools that help maintain the dementia sufferers' sense of self and self-expression as long as possible. This is a pragmatic reason why dementia requires loosening the narrow frames of Olympic rationality and lowering the high ambitions of human consciousness. Another reason is philosophical: the fact that sufferers display better cognition in certain situations, for example, when surrounded by family and friends, or in the midst of

³ Elster [1998].

⁴ Simon [1982].

artistic activities, is significant and thought-provoking. Is the hyper-rational model of human personhood correct? Are *homines sapientes* as thoughtful as they claim to be? What does dementia – this extraordinary state of body and mind, of increased dependency and intensified vulnerability – tell us about human nature?

Dementia highlights two hitherto neglected dimensions of personhood: emotionality and embeddedness. Emotionality, beside cognitive capacity, emphasizes the importance of emotional expressions and treats them as vital elements of human personhood. A person touched by dementia may not be able to express many of their wishes in an intelligible and sophisticated way, but retains their sense of preference, which can be worked out by tracing their emotional responses to certain propositions. The author of the Dementia Report describes the case of a woman with advanced dementia – a care home resident who, despite retaining very little cognitive capacities, could still remember dance steps and derived immense pleasure from dancing with her husband.⁵ Their monthly ‘dancing dates’ were the continuation of a lifetime habit and a way of preserving intimacy despite the illness. Emotions are not only an expression of satisfaction and an indication of preferences, as in the case of the dancing woman, but also a tool for preserving and enhancing cognitive capacities. As powerfully and beautifully depicted in a documentary entitled *I remember better when I paint*, creating a safe and emotionally-friendly surrounding may enable a person with dementia to preserve her cognitive capacities and remind her of the facts which seemed already forgotten.

This multiple function of emotions – as tools of life-satisfaction, preference indicators, and ‘cognition catalysers’ – is in accordance with the newest models of human rationality. Beginning from the works of Hebert Simon,⁶ the Olympic model of rationality is brought into question. The recent Noble-winning theory of bounded rationality highlights the closeness of the cognitive-emotional tangle, and exposes the deep rationality hidden in human emotional aspects. Daniel Kahneman and Amos Tversky describe human thinking as being composed of two modes: the first is fast, intuitive, and emotional, and operates quickly and automatically with little or no effort and no sense of voluntary control. The second mode is slower, more deliberative and more logical, and allocates attention to effortful mental activities. Of the two, it is the first one that gives us what we call intuition.⁷ This positive account of emotions, as involving deep but not always

⁵ Cf. NCoB [2009] p. 64.

⁶ Simon [1982].

⁷ Cf. Kahneman [2011].

realised cognitive judgements, is confirmed by contemporary psychology⁸ and is, apparently, not so foreign in philosophy either – as early as at the beginning of the 20th century, Max Scheler⁹ described emotions as a way of perceiving values and a tool for building a personal value hierarchy (as later proven by people with dementia communicating their preferences emotionally). These theories reinforce the thesis that the wishes of people with dementia should not be dismissed too quickly, just because of their difficulties expressing them. The deterioration of cognitive capacities usually takes a top-down route, that is, from the most sophisticated and effortful mental cognitions to the most basic and intuitive ones. Therefore, from the fact of the loss of one of the higher functions – the possibility of logical self-expression – a conclusion about the total loss of cognitive abilities should not be derived. In terms of the theory of bounded rationality, it may be said that despite losing some of the abilities of the slow-thinking mode, the dementia sufferer still retains their fast-thinking capabilities, which are expressed in the rationality of their emotions. The theory of bounded rationality helps to interpret the phenomenon of dementia, and dementia, in turn, with its sudden and emotionally valid cognitions, can also be treated as a precious contribution to this theory and further proof of the mysteries and the inexplicable nature of human personhood.

The second trait of human personhood emphasized by dementia is its embeddedness. The notion of embeddedness expresses the fact that a person is not an isolated individual, but a *zoon politikon* deeply rooted in social relations, which altogether shape their way of thinking, personal choices and identity. Personal identity, thus, cannot be reduced to self-consciousness, 'auto-narration' and individual choices, as it is also influenced by people with whom we live, the environments we engage in and the quality of the relationships we build. This social self is not only a border around our inner fortress but a vital part of it (how deep this entanglement is can be best illustrated by Wittgenstein's lesson on the impossibility of private language; the fact that even our autonomous, logical thinking is mediated by our social nature and the 'social gift' of language highlights the interdependency of our social and personal selves). This interdependency is clearly exposed by dementia sufferers: in numerous situations dementia patients tend to remember more and express their minds much easier if their relatives are around. The assistance of close relatives works like a safety net, which allows these vulnerable people not only to express themselves, but also – through the presence of those who help constitute their identity – to maintain their sense of self for longer.

⁸ Cf. Frijda [1988]; Nussbaum [2003].

⁹ Scheler [1913].

Expanding the notion of personhood entails expanding the concept of autonomy. The traditional concept of autonomy is negative: it defines autonomy as non-interference and the freedom to make independent decisions. The classic catalogue of patient rights, such as the right to information, the right to give or withhold consent to treatment and the right to privacy, is designed to promote this kind of autonomy. In the case of dementia, however, the notion of autonomy as ‘non-interference’ is insufficient, as it can be interpreted as ‘the right to be left alone’. This would, instead of expanding human freedom and well-being, lead to neglect and further degeneration of the dementia sufferer. In the light of the intimate influence of our friends and relatives on our social self and personal identity, involving them in the care of dementia sufferers (after first establishing their *bona fide*, of course) seems a reasonable thing to do. Such a step is proposed by the authors of an NCoB report on dementia, who develop a richer account of autonomy which they describe as ‘relational’. Their ‘relational autonomy’ starts from similar premises: that the wider notion of personhood is anchored in the social world, and the conviction that autonomy should not only be protected from interference but also actively promoted. Not surprisingly, the key role in the process of promotion is played by those who can understand what a person with dementia experiences, wants and feels ‘without words’ – their family and friends, their surroundings, and all those people connected to this person by deep emotional bonds.

2.2. The structural challenge

The concepts of social personhood and relational autonomy emphasize the role played by the dementia sufferers’ surroundings in the process of their care, thereby introducing the second – structural – challenge that we are faced with in the case of dementia. Dementia transforms not only the traditional concept of the person and their relationship with the world, but consequently also the mutual relations between different kinds of carers.

Given the progressive deterioration of cognitive capacities in dementia sufferers, their needs change progressively. In the first stage of the process, a person might be capable of living on their own, with sporadic help from relatives and friends. In the second stage, they become more dependent on the help of others, such as close relatives or friends. In the third stage, they cannot do without specialized medical or palliative care. However, the borders between these different stages are blurred, which raises the necessity of cooperation between different care providers, the coordination and continuity of care. Unfortunately, this is precisely what the healthcare system lacks, and this is to the detriment of the most important carers – the informal ones.

Informal care is usually provided by spouses, and also possibly adult children, sons- and daughters-in-law, friends, neighbours etc., with an overrepresentation of women (in Europe, around 76% of informal caregivers are female¹⁰). Informal family care remains the cornerstone of care for dependent elderly people all around the world, and rightly so, as it is provided spontaneously, for noble reasons. The main motivations for caregivers of dementia sufferers are love and affection, as reported by 57% of respondents in a 2012 WHO survey. A sense of duty was reported by 15%, and a personal sense of obligation by 13%. Only 3% of caregivers stated that they 'had no other alternative than to care'.¹¹ For many positively-motivated carers, providing care is a rewarding experience despite its hardships, allowing them not only to maintain intimacy with the sufferer, but also giving them a sense of fulfilment, meaning in their life, and self-esteem.

Despite the pivotal and undeniably beneficial role of this kind of care, informal carers are neglected. This is grossly unjust, as they bear a double burden: firstly, they are personally affected by the suffering of the afflicted, and secondly they themselves experience emotional, social and financial strain from caring. Constant exposure to these stressors raises the probability of affective disorders amongst carers. Data suggests that 22.3% of carers had a depressive disorder during the period of caring; 1 in 3 caregivers suffers from anxiety, and between half to three quarters of all caregivers experience the milder symptoms of depression and anxiety.¹² What is particularly affectively dangerous about dementia is its progressively degenerative nature, which can result in carers regarding their effort as Sisyphean, which increases the probability of developing affective disorders as dementia develops. Another negative impact is made by the economics of the situation. Intensive caring is a full-time job, which can become incompatible with a normal professional life and force the carer to reduce the number of paid working hours they can take, or even to quit their job, exposing them to the risk of prolonged unemployment or even poverty.¹³

Unfortunately, despite the crucial nature of informal care for dementia sufferers, as well as its dangers, it is often underestimated by social and medical services. This underestimation consists not only in the neglect of carers' own needs, their health and well-being, but also in the lack of trust from professionals who often choose not to share helpful information, discharging their assistance

¹⁰ WHO [2012] p. 69.

¹¹ *Ibidem*, p. 71.

¹² *Ibidem*, p. 73.

¹³ Colombo et al. [2011] p. 91-97.

and general lack of coordination between different kinds of care. The neglect of carers is reprehensible, not only for practical and moral reasons, but also for the financial ones. The costs of dementia care are still growing, and the society does not cease to age. These factors cause the third challenge dementia exposes us to – the financial one.

2.3. The financial challenge

Here statistics speak for themselves. Dementia costs will be soon ranked as high as the world's largest economy. For now, they range from 16th to 18th place, together with countries such as Indonesia, the Netherlands, and Turkey. In 2015 the global societal economic cost of dementia was USD 818 billion, compared to USD 604 bn in 2010 (a 35% increase). This gigantic sum is more than the market values of companies such as Apple (USD 742 bn), and Google (USD 368 bn).¹⁴ These costs are still increasing and will continue to do so as European society continues its rapid ageing: in 1950 only 1% of the global population was over 80; by 2050 this figure is likely to increase to 4%, with nearly 10% of that being in OECD countries.¹⁵ This brief statistical presentation is enough to help us understand the scope of the impending financial catastrophe, which can, however, be prevented by adopting a more solidary dementia policy.

3. Two models of solidarity: welfare-based and cooperative

3.1. The paradox of solidarity

At first glance, the statement that the global costs of dementia require a solidarity-based remedy may seem paradoxical.

On the one hand, dementia demonstrates the increasing need for solidarity. If man is not a perfectly rational or fully autonomous, and thus not self-sufficient, creature, then the only conclusion can be an obligation to mutual assistance. This insufficiency does not only concern dementia sufferers, but is part of our general human condition: frailty and dependency are deeply rooted in our limited human nature, and are stimulated by dementia (to which everybody is prone, according to the epidemiological statistics), any other illness or different kind of predicaments. Blaise Pascal was right: regardless of how hard we try to hide our fragility, we are 'hollow reeds, blowing in the wind'.

On the other hand, the increasing need for solidarity is related to the growing costs of health care. The concept of solidarity in healthcare is traditionally de-

¹⁴ Cf. Prince et al. [2015] p. 1.

¹⁵ Colombo et al. [2011] p. 13.

defined as an obligation to ‘help the suffering, the troubled and the disadvantaged’¹⁶, which in the European welfare system is treated as a state obligation. Janos Kornai completes this definition as follows: ‘It has to be prescribed by law that the state must help the suffering, the troubled and the disadvantaged’¹⁷ and Ruud ter Meulen adds: ‘In the European welfare state, the basic understanding of solidarity is that everyone is assumed to make a fair financial contribution to a collectively-organised insurance system that guarantees equal access to health and social care for all members of society.’¹⁸ This obligation is realized in a threefold way: as risk solidarity, establishing an allowance for people who, due to a congenital disease or disability incur higher risk and usually higher costs for healthcare insurers; as income solidarity, subsidizing the poorest; and as age solidarity, establishing an allowance for frail seniors who become frequent customers of healthcare. However, as the needs of ‘the needy’ are unending and the human and financial resources of healthcare very limited, uncritical solidarity would lead welfare arrangements to a dead end. The already enormous and ever-increasing global costs of dementia clearly illustrate this mechanism.

How, then, can the prevalence and growing costs of dementia appeal to greater financial expenditure? In view of the demographic reality, such an appeal seems irresponsible. So how to solve the contradiction between the increasing need for solidarity and its diminishing affordability? To answer this question properly, we have to take a closer look at the concept of solidarity itself. Among many different interpretations of this notion, the ‘welfare-based’ and ‘cooperative’ versions of solidarity are of the highest relevance in this context.

3.2. Welfare-based solidarity

The paradox of solidarity discussed above is caused by its having a distorted model. Nowadays, solidarity is associated with the phenomenon of welfare-based solidarity. This kind of solidarity postulates an ideology of state protection (‘solidarism’), rather than the free, spontaneous cooperation of citizens. It is based on three premises: the first is the above-mentioned ideal of helping the suffering, the troubled and the disadvantaged. This help, as Ruud ter Meulen postulates, thus formulating the second premise, should be organized as a common enterprise (such as a collectively-organised insurance system). The third premise ascribes the accomplishment of the obligations of solidarity to the state. The first two premises express the notion of solidarity itself, and the obligations following from it. The

¹⁶ Kornai, Eggleston [2001] p. 17.

¹⁷ Ibidem, p. 18.

¹⁸ ter Meulen [2015] p. 4.

third premise refers to its legal transcription – it places these obligations on the state and its ‘benevolent’ institutions that promote people’s welfare.

Economic arguments against welfare-based solidarity are clear. The idea of state protection, equal, unlimited access to medical goods and special care for the most vulnerable is admittedly a noble and beautiful idea, but plainly unrealistic in a world marked by human finitude and limited resources. In the domain of medicine, this shortage is particularly visible: the ageing of the European population is the reason for both the increase of its medical needs and decrease of its vitality, and thus financial potential. And after having described the financial dangers of dementia, one does not need to further demonstrate that this economic reality is the case. But what is more controversial about the welfare state is its apparent moral legitimation and public attachment to this idea, which causes populist outrage when the fundamentals of welfare guarantees are questioned. However, the moral legitimation of the welfare state is not so obvious.

The main moral arguments against this welfare-based model of solidarity are directed at the third premise. They question the ascription of the obligations of solidarity to the state and thus, indirectly, the idea of the welfare state itself. On ter Meulen’s¹⁹ account of solidarity, reference is made to the idea of decency, promoted by Avishai Margalit. Margalit sets the social arrangements in the order of growing perfection, beginning from civilized society, through decent society, then just society, with the society of solidarity as the most advanced form of social development. Decency, thus, is a precondition of solidarity, the realization of which cannot be accomplished when decency is infringed. The infringement of decency is ‘any behaviour or condition that constitutes a sound reason for a person to consider his or her self-respect injured.’²⁰ Margalit rightly observes that the welfare-state institutions tend to humiliate citizens with their essential paternalism and humiliating procedures which are necessary in obtaining their due rights. As proved by empirical research, administrative benevolence results in three kinds of unfavourable consequences: 1) the growing costs of care as an extension of administrative benevolence is expensive; 2) the ‘crowding out’²¹ of private, spontaneous benevolence, private solidarity and, as with dementia, family care; 3) the ‘learned helplessness’²² of beneficiaries, whose capacity for free action is brought into question by depersonalised and standardized institutional help. The difficulties of de-

¹⁹ ter Meulen [2011].

²⁰ Margalith [1996] p. 9.

²¹ Bohnet [2001].

²² Dixon [2012].

mentia care, which fit into the welfare-based schema, are the best example. Home care, hospitals and other formal institutions are necessary, but not the most needed by dementia patients, who prefer to and can be successfully cared for by their family members. However, tax-based resources, rather than in facilitation and coordination of family care, are invested mainly in the extension of formal institutions, which are not only less efficient, but also have higher maintenance costs. This creates an illusion of solidarity: society proves its solidarity with ‘the needy’ by the extension of a formal system of care while family carers who display spontaneous solidarity with dementia sufferers are neglected or even crowded out by the state’s over-action.

The critics of welfare-based solidarity cite not only the third premise of its organizational aspect and ascription of solidary obligations to the state, but also the content of the idea conveyed in the first two premises. Obviously, the philosophical content of the idea defines the shape of its legal transcription. The first two premises present the idea of solidarity as the combination of cooperation (‘collectively-organised insurance system’) and support (‘help the suffering, the troubled and disadvantaged’). Solidarity is understood here as a common enterprise of humanitarian help. As a symbol of association based on solidarity, such organizations as ‘Doctors Without Borders’ – an organisation providing voluntary humanitarian aid to the poorest and neediest – stand out. While it is undeniably true that the two elements of cooperation and support are essential to the bond of solidarity, its aim cannot be reduced to humanitarian aid alone. In the helping relationship, especially government-provided help, there is an inherent danger. Even in the case of generalized, institutional help, which is not directly provided out of pity or compassion, these legitimations often refer to such feelings indirectly. Obviously, pity cannot be easily identified with compassion and the well-known acute Nietzschean criticisms of these feelings may seem too sharp and too far-reaching in the case of humanitarian help. But still, it reveals the dangers of this asymmetry of power and status, which is one possibility inherent in the ‘master and servant’ relationship. The phenomenon of ‘learned helplessness’ confirms the possibility of this scenario. Another danger of compassion in politics is Parfit’s famous objection of levelling down²³ – politics ruled by pity for *les misérables* often results in an ‘egalitarianism of envy’, which often results in worsening the situation of the most affluent and privileged.

The main objection to the ‘humanitarian’ version of solidarity, which is written under welfare arrangements, are not its paradoxical causes. These are

²³ Parfit [1997].

rather a consequence of its distorted model which does not fully do justice to the nature of solidarity. The latter will be exposed with the example of a cooperative version of solidarity.

3.3 Cooperative solidarity

The elements of cooperation and mutual help are constituent parts of solidarity. This notion stems from Proto-Indo-European **solh₂id^hos*, a suffixed form of the root **solh₂-* ('integrate', 'whole'), with the Latin '*solidus*', meaning '*firm, dense, compact, not hollow, solid*'.²⁴ It calls directly back to the ancient Roman legal institution of *obligatio in solidum*, which was the obligation undertaken by partners in a joint venture. This was an obligation of a special, radical nature, under which each member of a business partnership was responsible for the entire debt. The radical nature of this obligation can be briefly but accurately expressed by the famous catchphrase of those noble friends, the three musketeers: 'One for all, and all for one'. As in the friendship of those gallant knights, the *obligatio in solidum* requires special, gentle features of character and a deep, mutual trust – the decision to take on such a radical responsibility presupposes a special quality of relations between the partners of an enterprise. In relation to this original, etymological meaning, solidarity on a wider social scale is often described as being a 'civic friendship'.²⁵ The example of friendship, whether interpersonal, legal or social, displays the main features of solidarity. These are: 1) an attitude of cooperation, often undertaken for a higher, 'noble' aim; 2) a bond of trust, which emerges in the course of spontaneous, value-based cooperation, and as a form of social capital fuels the cooperation itself, and 3) radical individual responsibility for the common enterprise, which is the responsibility for its gains, losses and debts.

This radical responsibility 'for good and for bad' includes an obligation to mutual help in the case of emergency. At first glance, this model of solidarity adds nothing new to its humanitarian version – here, too, solidarity is composed of two elements: cooperation and mutual help. However, in the context of cooperative solidarity, this help has not a humanitarian, but a restorative character – it is not provided out of pity or compassion, but out of previously undertaken responsibility. As such it preserves the liberal, and thus liberating character; help provided out of freely undertaken responsibility has a different, less 'addictive' character than help provided out of emotional necessity or the lust for power. Its aim is also different, which is not only the relief, but the restoration of impaired cooperation.

²⁴ <http://www.perseus.tufts.edu/hopper/text?doc=Perseus:text:1999.04.0059:entry=solidus> [15.9.2016].

²⁵ Cf. Brunkhorst [2005].

Hannah Arendt could be considered an intellectual patron of this kind of solidarity. In her excellent book *On revolution*,²⁶ she presents an original account of solidarity as a ‘common action’. In this account solidarity is a non-emotional alternative to relations based on pity or compassion. What unites people in common action is not pity or other feelings, but perception of common values and interests. Among these interests the most important ones are freedom and human dignity. As such, solidarity is a revolutionary concept: not only does it strive for freedom (in the context of political revolution), but realizes it in the course of common action.

3.4. Solidarity and reciprocity

Both versions of solidarity lie very close to each other. In the previous section, as an example of humanitarianism, solidarity was presented in the form of the charitable *Médecins Sans Frontières* organization, which offers benevolent help to the neediest and poorest inhabitants of the earth. Of the different kinds of cooperative solidarity, the prime example of the Polish trade union can be offered. Known in Latin as *nomen omen*, and to modern man as Solidarity, this was one of the most beautiful historic examples of civic friendship. Polish ‘Solidarity’ encompassed two previously-mentioned dimensions: it was a ‘revolutionary association’ fighting for freedom under totalitarian rule, and also a kind of cooperative, whose members offered each other mutual help in cases of dismissal from their jobs or persecution. The example of Polish ‘Solidarity’ illustrates well the liberating and restorative potential of mutual support. As many members of the legendary Polish trade union confirm,²⁷ their mutual support worked as a safe ground that enabled them to speak their minds freely, in confrontation with the political (and professional, as they often coincided at that time) powers-that-be. Thanks to this ‘safety net’, they could hope that in the case of their dismissal, there would be someone to help them get back on their feet. Thus, instead of teaching helplessness, solidary assistance empowered and enhanced cooperation, proving the authenticity of civic friendship (‘solidarity in need is solidarity indeed’).

This liberating power was enabled by the symmetrical character of the relationship between the members of this association. Originally, both its benefactors and beneficiaries were ‘civic friends’ – they had primarily equal positions and their trouble-driven asymmetry was of an accidental and temporal character. In the case of humanitarian help, the situation is essentially different. Here, the relationship is not only primarily asymmetrical, but constituted by this asymmetry:

²⁶ Arendt [1963].

²⁷ Cf. Krzemiński [2013].

the affluence, the surplus of resources enables the benefactor to support the beneficiary in need. In the case of the welfare-state (or different kinds of state aid), support for this asymmetrical distribution of power reaches an extreme, as here a vulnerable individual is confronted with the 'omnipotent' powers of the Hobbesian Leviathan. However, even in the case of the most humbly and benevolently provided medical aid, this relational asymmetry is irreducible and can have an addictive character for its recipients. The members of a solidary association have the experience of partnership, they do not cease to be partners in a situation of difficulty and their mutual support is aimed at restoration of the original partnership, and this cannot be said about asymmetric humanitarian help. Obviously, it does not question the necessity of such benevolent support, but requires distinguishing from the relations of solidarity. This difference can be most clearly presented in the cited example of the Doctors Without Borders organisation. The notion of solidarity can be applied to it as far as the relations between the doctors engaged are concerned. The members of the organization who work together for the noblest of all noble causes – humanitarian aid – trust and assist each other, and in doing so display true solidarity. However, their asymmetric relationship with their patients is essentially different, and could be described as benevolence, mercy, compassion, or on a wider view which speaks of belonging to 'the family of man' – fraternity.

Why is reciprocity so important? It is the basis of every true friendship and also of civic relationships. As Aristotle argued in his classic and beautiful theory of friendship,²⁸ friendship requires a reciprocal exchange of goods: in a pure and true friendship, 'like' is paid with 'like'; in a 'friendship of interest', favours are paid with favours, and in a friendship 'for pleasure', needs and desires are mutually satisfied. Although only the first kind of relation can be called 'friendship' in the full sense of this word, as it is based on a free choice of the person of a friend (similarly, solidarity as a form of civic friendship is most complete if based on a perception of common values and love for the common good, instead of interests or needs). Each of these relations is based on the reciprocal exchange of goods 'in kind'. Violation of this balance must be compensated by paying back the debt with other kinds of goods. As Aristotle puts it, a person who likes more must pay their indifferent friend with additional admiration or favour. The same rule of reciprocity also functions in a civic relationship, which must be based on isonomy – the correspondence of rights and obligations. In civic relations, the lack of this reciprocity also has a high price: the Hobbesian Leviathan sells safety for freedom, excessive class disproportions trigger social revolutions, and welfare-based solidar-

²⁸ Aristotle, *Nicomachean Ethics*, bk. VIII.

ity teaches helplessness. On the other hand, as proven by contemporary research on social capital, civic friendships and trusting cooperation are the irreplaceable powers contributing to the wealth of nations to a great extent.

The inherent reciprocity of family and friends' relations also explains the success of informal dementia carers. As already proven by the sociological research, cited in the first part of the article, such care, despite its difficulties, is rewarding in itself, as it allows for the maintenance of intimacy with one's suffering loved ones, and in turn, being provided out of love and affection, it does not humiliate or disempower dementia sufferers. Naturally, this does not invalidate the necessity of also providing formal, professional care, but by emphasizing the advantages of spontaneous bottom-up solidarity it does show that this is a domain worth investing. The cooperative model of solidarity is not only cost-effective, but philosophically justified. It corresponds to the original meaning of solidarity and historical modes of its functioning, as well as to the vision of relational personhood presented in the first chapter of this essay. Cooperative solidarity emphasizes both sides of human nature: its relational aspect, the human necessity to be embedded in a larger entity, the ability to trust and cooperate, as well as our irreducible individuality, expressed in the radically individual nature of responsibility.

Despite all its assets, this model is most in need of legal transcription. As Durkheim rightly argued, observing in his epoch a transition from automatic to organic solidarity, the period of 'paradigm shift' is always marked by legal 'anomie' – a state in which the old moral and legal norms do not function properly any longer, while the new ones are not yet fully developed. Although the cooperative model of solidarity is still *in statu nascendi*, we can discern its general features. Obviously, criticism of excessive state protection is not automatically a plea for a minimal state. The cooperative model of solidarity still needs to provide, as ter Meulen would put it, a 'decent minimum of health care'. And as has already been argued, this requirement of decency is directed against institutional humiliation and excessive 'solidarism'. Instead of extending formal care beyond measure, part of the resources could be transferred to building channels of cooperation, promoting and facilitating bottom-up cooperation and mutual assistance, as well as enabling private and public partnerships. Dementia, with its growing costs on the one hand, and its relatively deep embeddedness in informal structures of care on the other, is a testing ground for these new ideas, and the new, emerging model of supportive care proves its feasibility.

4. Solidarity in dementia care. The supportive care approach

4.1. Cooperative solidarity in health care

The concept of cooperative solidarity is slowly emerging in dementia care, and the NCoB's recent Dementia Report can be seen as a proof of this process. Its authors use the concept of solidarity in the field of bioethics, medicine and health-care in a creative way, thus proving that it is still a powerful and inspiring idea that can operate as an engine of change. They define it briefly as the conviction that 'we are all "fellow-travellers" and that we have duties to support and help each other and in particular those who cannot readily support themselves'.²⁹

This definition can be completed by the one proposed in another NCoB report, dedicated this time entirely to the concept of solidarity. Solidarity, it asserts, means shared practices reflecting a collective commitment to bear the 'costs' (financial, social, emotional or otherwise) of assisting others, which follows from the recognition of sameness or similarity in at least one relevant respect.³⁰ This definition clearly shows that the authors of both reports think about solidarity in a cooperative way, as primarily a relation between symmetrical fellowship and collective commitment, following from some form of similarity or commonality (shared identity, common cause, common values) with the secondary obligation to bear the mutual costs. It is undeniably true that solidarity finds expression in emergency situations, when we have to help one another and prove the authenticity of our collective commitment to carry mutual burdens ('solidarity in need is solidarity indeed', as it has already been said). One such emergency is the challenging situation of dementia. However, even if people so affected are in a situation of dependence, vulnerability and the aforementioned asymmetry, the authors of the report rightly emphasize their cooperative potential, writing that 'those receiving care and support should not be seen simply as people with particular rights or as victims of a disease or disability, but rather as citizens with both their own needs and a societal role'. It is clear that this kind of solidarity should not be provided out of pity or mercy towards dementia sufferers, but from recognition of their still valid social role and the reciprocal contribution they can make.

The authors of the Dementia Report propose a different model of solidarity in healthcare than that provided under its traditional welfare-based understanding. Collective commitment to bear the costs is not exhausted by tax collection, through which administrative help and institutional benevolence are then financed. Although institutional help is indispensable (especially in the last stage of

²⁹ NCoB [2009] p. 29.

³⁰ Buyx, Prainsack [2011] p. 46–50.

dementia), reducing the content of solidarity to a formal arrangement would deepen the feeling of helplessness felt by people touched by dementia, as well as their relatives. This would result in their further exclusion from 'normal' social life, which for a long part of dementia's development could be avoided. The authors of the Dementia Report therefore propose a twofold model of cooperative solidarity, which corresponds to its general features, as described above. This model requires, firstly, the provision of a decent minimum of professional help for those who cannot readily help themselves, and then direct themselves for help to those who already do help in a spontaneous, benevolent and natural way, namely informal family carers. In this cooperative vision, it does not suffice for solidarity to establish institutions of formal care, but requires above all the building of channels of cooperation between the different care providers, including those who have become dependent and frail in their 'normal' social life as far as possible. The state, with its administrative powers, fulfils here only a subsidiary, cooperative role.

4.2. A supportive approach – the emergence of a new paradigm

The first indication of this paradigm shift can be found in reference to the evolution of the model of care for dementia sufferers. Clarifying the image of dementia has substantially contributed to its evolution. Julian C. Hughes accurately reconstructs this process.³¹ Because of the complex nature of dementia, which has biological, mental and social dimensions, the previously dominant biomedical and psychosocial care models appeared to be irreducibly unilateral. The biomedical model, which emphasized the illness, regarded dementia sufferers and their carers as patients and offered them strictly pharmacological treatments, played down the social aspect of dementia and disregarded the patient and his individual needs. The psychosocial model, on the other hand, stressed the importance of the individual and their psychological and social life, and thus neglected the biological side of dementia.

The first solution to this impasse of unilaterality was the palliative care movement. Its main advantage was a holistic approach encompassing the biomedical, psychosocial and spiritual, and concern for the psychological wellness of the family, especially during periods of bereavement. However, the main achievement of palliative care, the abolition of the dichotomy between cure and care, does not fully suit the nature of dementia. The palliative care approach stems from end-of-life contexts such as cancer care, where a cure is no longer possible.

³¹ Hughes et al. [2010].

But dementia is different: despite its progressive nature, many symptoms can be alleviated, and it is often curative actions which bring the best palliation. Going further, the supportive care approach utilises a framework that unifies all former aspects in a creative way. It draws on the holistic approach of the palliative model (in the sense that it should emphasize the quality of life and take into account spiritual needs) without resigning from pharmacological treatment. The most important *novum* of the supportive care framework is that it adds to the previous models' greater appreciation of the role of family. Family members are not taken into account exclusively during the period of bereavement, but are primarily treated as 'partners in care', worthy of support in their own support of the dementia sufferer, and also as 'subjects of care' being in need of support themselves.

4.3. Tools of solidarity: supportive care in practice

Supporting family carers is a 'win-win-win approach'³². First of all, it is highly favourable for the dementia sufferers, being the main subjects of supportive care. This is not only because people generally prefer to be taken care of by those who really care for them, out of love and affection. Care for their family carers also touches dementia sufferers personally. This conclusion follows from the expanded notion of personhood presented in the first part of this article. Within these expanded frames, close social relations are treated as part of the self and a necessary condition for maintaining one's identity. In order to keep the sense of the self of dementia sufferers and enable them to exercise 'relational autonomy', it is thus necessary to support the whole family and social structure that they are rooted in. Another 'win' in caring for carers is offered to the state. In light of the above-presented statistics, it is clear that the only affordable strategy for managing the increasing threat of dementia epidemics is through informal carers. Finally, as the carers are often over-worked and brought to their emotional, physical and financial limits, caring for them is our moral obligation, and as such a moral win.

The Alzheimer's Society³³ postulates a series of actions to relieve carers, which can be classified into three general groups: actions designed to offer respite, counsel and emotional support to carers; actions aimed at including carers in formal care processes (e.g. providing them with necessary information, advice and guidance, involving carers in decisions on care and support, coordinating their work with the work of medical staff), and finally, means of financial support. Another important kind of actions, not mentioned by the Alzheimer's Society but af-

³² Colombo et al. [2011] p. 121.

³³ Cf. https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=546 [15.9.2016].

fecting the wellbeing of carers in an essential way, are actions intended at combating the stigma attached to dementia and promoting the social inclusion of people touched by dementia and their relatives.

a) Personal support

The most important field of action is undeniably the first one. Offering carers emotional counselling and physical respite not only gives them the possibility of restoring their strength, but is also the right way to recognize the significance of their work and show them due respect. This kind of support is provided in many forms, with respite care being the most common. The aim of respite care is to alleviate the burden of care by providing a temporary pause (varying from 'day-breaks' to long-term breaks) from caring. This can be achieved through various means, such as day-care services, in-home respite and institutional respite.³⁴ Although the necessity of respite seems obvious and such help is easy to get without external help, arranging and offering respite care 'institutionally' is more important than it seems. Many carers often hesitate to take such breaks because they are uncertain about the quality of care they will leave the person they are in charge of with, as well as the financial difficulties they often struggle with. Another important action in this domain is counselling. This also has two dimensions: one aimed at the carer and their own emotional needs and problems, the other at the person they are taking care of. Offering a carer 'professional training' is also very important, as they know the sufferer much better than medical and social staff, and can provide qualitatively better and more effective care, despite usually lacking professional knowledge of the nature and process of dementia. Providing a carer with even the most basic information can spare them a lot of stress and feelings of helplessness and defeat that they often experience due to their lack of knowledge. Such emotional counselling and 'professional training' is offered by private non-profit organisations (such as various national Alzheimer's societies), or sometimes simply by other more experienced dementia carers. Unfortunately, many carers are not aware of the services available to them. This highlights the need to improve information and coordination services.

b) The coordination of care

The adherents of the 'supportive care approach' unanimously emphasize that it can be achieved in small logistical steps, the first of which is coordination of different services.³⁵ They propose the introduction of a care-manager, or care-

³⁴ Colombo et al. [2011] p. 121-159.

³⁵ Hughes, Williams, Sachs [2010].

coordinator, who would provide continuity and advice on all avenues of care, especially in the period of transition from a milder to a more severe stage of dementia. This type of 'key-worker' has already been introduced in different countries. England has an institution of specialized 'admiral nurses' who visit carers and dementia sufferers in their own homes to deliver education, training and support. The Dutch system, which has undergone a transition from 'nursing home medicine' to general and less institution-focused 'elderly medicine', also operates similar coordinative services.³⁶ Germany has Social Services Centres which evaluate carers' needs, inform and support them throughout the caregiving process and coordinate their work with the work of medical and social services. A parallel function is performed by the Vienna Health and Social Care Centres and Tyrolean Integrated Social and Healthcare, in Austria.³⁷

Of all these different solutions there is always one that seems to suit every healthcare system. In most cases, primary care physicians are ideally suited to the role of 'care-coordinator'. They have most of the knowledge about a dementia sufferer and his/her family, and should also be best informed about the possibility of community support networks and private care arrangements. Finally, they are able to recognize changes in the clinical condition of the person and her actual needs and direct her to appropriate specialist or institution. Therefore, instead of being a gate-keeper who restricts access to care – which, as the analysis by Consumer House proves, is not necessarily as cost-saving as it is often said to be³⁸ – the GP should instead be open to the possibilities of better, more integrated, and efficient care and serve as a liaison between different services.

Gillie E. Evans and Louise Robinson³⁹ propose a supportive care model based within primary care, in which the GP would be responsible for a patient throughout the entire course of their illness, from diagnosis to death. The role of the GP in the preliminary state of the illness (before and just after diagnosis) is invaluable. It can shorten the path from the initial revealing of suspicious symptoms to confirmation of a diagnosis, which may be crucial for the good preparation of future care, making important decisions and arrangements, leading conversations with relatives and friends, and preparing advance care statements and other documents if a national legal system allows it. Another important moment which should be taken care of is the moment of the confirmation of a diagnosis. Saying

³⁶ Hertogh [2010].

³⁷ Colombo et al. [2011] p. 132.

³⁸ Björnberg [2015].

³⁹ Evans, Robinson [2010].

‘the D word’ openly, as Evans and Robinson eloquently name it, can have far-reaching repercussions for the entire future process of coping with the condition. As the patient’s dementia develops, the GP’s tasks will change too. In later stages, the role will become one of a coordinator’s, rather than a counsellor’s, with more management and integration of different kinds of care than administering it himself. It can still, however, be life-saving in emergency situations, when every minute counts and the right decisions need to be made quickly. Finally, the GP can adopt a proactive attitude and motivate all of the different carers, from relatives to specialists, to contribute to the improvement of the level of care provided, and enter into further mutual cooperation.

c) Maintaining trust

Work with carers should encompass protection of their personal relationship with the people they care for. This relationship is based on trust, and this trust should be maintained and expanded. Maintaining a trustful relationship is not only a sign of respect for the carer, but another necessary condition for promoting the relational autonomy of the dementia sufferer. To protect this relationship, the authors of the Dementia Report formulate an ethical imperative for professionals to start from a presumption of trust in the carer, their *bona fide*, and in their knowledge of the dementia sufferer, which should last unless there is evidence to the contrary.⁴⁰ This presumption should have a legal consequence in an obligation to disclose confidential information on the medical condition to the informal carers of a dementia sufferer lacking legal capacity, when it is in the sufferer’s best interest. However, loosening the restrictions on such disclosures requires, in many legal documents, the guidance of medical professionals on the nature of the information the carers may need, and the reasons for disclosing it. (The possibility of abuse on carers’ part cannot be excluded.) Above all, it requires creating a ‘care partnership’ and building dialogue between all the parties concerned.

d) Financial support and social inclusion

Another way to recognize and respect the work of carers is by providing financial support to them. This is also a policy originally proposed by the Alzheimer Society. They argue that despite the fact that carers create huge savings for the national economy (in the UK, this is an estimated 11 billion GBP every year, just from the Alzheimer’s Society⁴¹), they often run into financial difficulties them-

⁴⁰ NCoB [2009] p. 120-122.

⁴¹ Cf. <https://www.alzheimers.org.uk/statistics> [15.9.2016].

selves. Therefore, financial support is often regarded as an expression of concern and solidarity. There are two basic forms of financial support. The first are financial allowances paid directly to carers. These are also divided into two basic forms: in the Nordic countries (Denmark, Finland, Norway, and Sweden), family carers are remunerated in the form of a standard salary, as they are formally employed by long-term care institutions, whereas in English-speaking countries (Australia, Ireland, New Zealand, and United Kingdom), allowances are 'means-tested', and as such reserved only for carers 'in financial need'.⁴² The authors of an OECD report rightly observe that, in practice, both forms of allowances can potentially be abusive. They have many eligibility requirements for the carer, the level of care provided and the relationship between the carer and the recipient of care, which may be very difficult to assess administratively, could be perceived by carers as arbitrary, and in consequence lead to injustice (e.g. by remunerating only one of many family carers). The second form of financial support is indirect. This time, it is the recipient of care who receives a cash benefit instead of equivalent services in kind (e.g. personal budgets in Germany and the Netherlands), with which they can 'hire' their family carers formally, and pay them for care which they rate as better, more efficient and trustworthy than that provided by an external nurse, etc. This can, however, lead to the financial dependence of the carer, trapping them in a low-paid and low-skilled job, discouraging them from raising their qualifications and getting a better-paid job. Creating financial dependence in the carer can also deepen their emotional and physical entanglement and increase their likelihood of developing a serious illness. The most important threat is, however, the potential monetization of family relations. Usually, informal care is provided for emotional reasons (love, affection, trust, gratitude) or for noble reasons (a sense of obligation, stewardship), which are rewarding in themselves and constitute the uniqueness and intrinsic value of informal care. Introducing financial arrangements into relations based on trust and affection can crowd out these virtues. Providing financial incentives can also attract groups of carers acting with 'bad motives' and undermine the existing intrinsic 'good motives'. Still, in many situations, providing family carers with financial support seems unavoidable.

A much better way to support a family carer financially is to help the carer reconcile their work and care (e.g. through flexible work arrangements or by granting them leave from work). Combining professional work with home care can be a challenge, both for the carer and the employer, but the benefits it can bring are invaluable. Professional work, apart from protecting financial security,

⁴² Colombo et al. [2011] p. 121–159.

can paradoxically offer respite to a carer, allowing them to focus on something else than a loved one's illness and raise their feeling of self-efficiency – crucial in the struggle with the non-conquerable illness that dementia is. This strategy is also much more solidary in the sense of the above-presented cooperative understanding of solidarity. Although giving money may be perceived as a better and more solidary solution than multiplying formal institutions, it still operates within the paradigm of 'humanitarian solidarity'. Cooperative solidarity not only obliges us to reinforce private cooperation and spontaneous initiatives, but also to do so in a cooperative way. Widening our social horizons enough to encompass dementia sufferers and their carers is a more challenging and much more solidary way of working than treating them as an 'underclass'. Working with carers and creating possibilities for them to participate and contribute in a '*normal*' social life requires a lot of education and effort on the part of administrative help, employers, co-workers and society in general. This could be an important asset in the struggle with the social stigma attached to the dementia sufferers and their often overloaded and tired carers, which results in their social exclusion and solitude: burdens often much harder to bear than the illness itself.

5. Conclusions: 'solidary transformation'

Dementia is a challenge. It crudely exposes places where healthcare and social care need improvement. Healthcare is too exclusive and confined, focused on its own actions and achievements and reluctant to cooperate with social and informal care. Healthcare professionals are, respectively, too narrow-minded and distrustful, operating in a 'gate-keeping' instead of 'horizons-widening' way. The horizons which really need to be opened encompass not only the way in which healthcare operates, but also the traditional view of healthcare, the understanding of dementia as a health condition itself, and, last but not least, the concepts of human personhood and autonomy. Dementia – as every challenging situation – provokes a paradigm shift in these domains, and can be regarded as a 'fortunate crisis' that has already forced us to think about and seek new ways of expressing rationality and freedom (e.g. 'relational personhood and autonomy'), as well as other ways of using human and financial resources (e.g. the 'supportive care approach') and it can be hoped that this development will continue successively.

Solidarity is a challenge as well. The authors of the Dementia Report⁴³ garnish their reflections of solidarity with a quote from Charles Dickens' *Christmas Carol*:

⁴³ Cf. NCoB [2009].

[...] when men and women seem by one concept to open their shut-up hearts freely, and to think of people below them as if they really were fellow-passengers to the grave, and not another race of creatures bound on other journey.⁴⁴

This short quote highlights the demands of solidarity. Solidarity is not only an obligation to help the poor, the sick and the needy, who are treated as ‘another [dependent] race of creatures’, but above all an invitation to open our own horizons wide enough to see fellow travellers and friends in other human beings who are often frail and weaker than we are. This, however, requires acceptance of our own vulnerability and finite human condition. Exercising cooperative solidarity is thus much more challenging than exercising welfare-based solidarity, as it requires not only the provision of external help, but also transformation of the way we see our beneficiaries, as well as the view of ourselves as benefactors. But it is also more rewarding, as it invites us to fellowship with others, and the joy of trust and cooperation are invaluable rewards of this ‘solidary transformation’.

Healthcare is the testing ground for cooperative solidarity, as well as its promised land. This is not only because of the founding role solidarity plays in healthcare, medicine and bioethics, but also due to the fact that in this domain, social institutions interfere with the everyday life and health of citizens to the greatest extent, and their shape and way of functioning is of primary importance to every citizen (in this sense, healthcare is a critical point of contact for the private and public spheres). Advancement of solidarity in this domain will not only improve our health and well-being, but can also become a cornerstone in building a more solidary and trust-based society.

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⁴⁴ Cf. *ibidem*, p. 29.

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