

22 International  
Conference

# Long-Term Care

Toruń, 18-20 September 2019

Global challenges in aging:  
Alzheimer's disease and other forms of dementia

How to improve the quality of life of people living with dementia  
Good practices from around the world

Conference materials

Organizer:



Partner:



## CONFERENCE PROGRAMME

---

18th September 2019

---

**18:00 CEREMONIAL INAUGURATION**

Can we protect ourselves against Alzheimer's disease?  
*prof. Maria Barcikowska PhD /Poland/*

---

19th September 2019

---

**09:00 - 11:00 SESSION I: A POSITIVE APPROACH TO ALZHEIMER'S CARE AND OTHER FORMS OF DEMENTIA.**

*Teepa Snow /USA/*

**11:15 - 13:15 SESSION II: ON THE OTHER SIDE OF THE MIRROR: DO WE PROPERLY UNDERSTAND WHAT WE SEE? EXPERIENCES OF PEOPLE LIVING WITH DEMENTIA.**

*Moderator: Teepa Snow /USA/*

Living with dementia  
*Jennifer Bute PhD /UK/*

Advanced Dementia: Towards Best Practice 3  
*prof. Debbie Tolson PhD /Scotland/*

My inner voice speaks your words. Language in building a care partnership.  
*Leszek Guga /Poland/*

Decision-making on behalf of people with advanced dementia 6  
*Jayne Murphy, BSc(Hons), MA, SFHEA, QN /UK/*

**14:00 – 15:30 SESSION III: ONE'S ENVIRONMENT MATTERS: WHAT CAN WE DO TO MINIMIZE THE NEGATIVE SYMPTOMS OF DISEASE AND TO IMPROVE BOTH QUALITY OF LIFE AND THE COMFORT OF CAREGIVING?**

*Moderator: prof. Debbie Tolson PhD /Scotland/*

3 Pounds of Hope  
*Sarah Brown /USA/*

Creating a Safe and Friendly Environment: How it Affects Abilities and Behaviors  
*Teepa Snow /USA/*

**16:00 - 18:00 SESSION IV: TALKING ALZHEIMER'S WITH A SPECIALIST: DO WE KNOW A CURE?**

*Moderator: prof. Piotr Błędowski PhD/Poland/*

Alzheimer's Disease – Early diagnosis and therapeutic support

*prof. Maria Barcikowska PhD/Poland/*

The importance of nutrition in the management of dementia

*Agnieszka Guligowska PhD/Poland/*

**19:30 INTEGRATION EVENING DINNER**

CT PARK, ul. Szosa Bydgoska 3, Toruń

*prof. Debbie Tolson PhD*

## Advanced Dementia: Towards Best Practice



*In 2013 Debbie was appointed as the Alzheimer Scotland Professor of Dementia and inaugural Director of the Alzheimer Scotland for Policy and Practice at the University of the West of Scotland. She is a registered nurse with an international reputation as a nurse leader and educator. Her professional standing is reflected in her Fellowship of the Royal College of Nursing, Honorary Fellowship of the Queens Nursing Institute Scotland and Principal Fellow Status with the UK Higher Education Academy. Research interests include caring interventions and practice based research designed to inform and improve advanced dementia care in the community and within nursing homes within Scotland, Europe and beyond.*

### The Development Agenda

It is almost a decade since the publication of the Global Development Agenda for quality of care in nursing homes by the International Association of Gerontology and Geriatrics (IAGG)<sup>1</sup>. However, the recommendations are as relevant today as they were then and extend across four domains:

- 1) Reputational Enhancement and Leadership,
- 2) Clinical Essentials and Care Quality,
- 3) Practitioner Education
- 4) Research.

The IAGG White paper prompted a series of international research studies and reviews exploring in more detail aspects of nursing home practice in different countries identifying priorities for improvement.

Due to rising demand for long-term dementia care and variations in standards, dementia care was identified as an improvement priority. A review of nursing home practice in Central Europe reported high restraint use, poly pharmacy including inappropriate psychotropic drug use, and inadequacies in the alleviation of depression and pain<sup>2</sup>. The review acknowledged that the quest to reform and improve the quality long-term care is complex, and that international collaboration and knowledge exchange is required to accelerate reform.

This paper explores the lessons for nursing home practice in relation to advanced dementia care arising from the *Palliare Project* [undertaken by a collaboration of seven European Countries](#) (Czech Republic, Finland, Portugal, Scotland, Slovenia, Spain and Sweden). The *Palliare Best Practice Statement*, discussed in this paper is an interprofessional learning framework revealing the complexity of advanced dementia care needs setting out what practitioners need to know<sup>3</sup>. It is a call to action to educators, managers and care providers to invest in evidence-based nursing home practitioner education underpinned by rights based values.

### Dementia Care a Priority for Nursing Homes

<sup>1</sup> Tolson D, Rolland Y, Andrieu S, Aquino J-P, Beard J, Benetos A, Berrut G, Coll-Planus L, Dong B, Forette F, Franco A, Franzoni S, Salva A, Swagerty D, Trabucchi M, Vellas B, Volicer L, Morley J E. The IAGG WHO/SFGG (World Health Organization/Society Française de Gérontologie et de Gériatrie). (2011) International Association of Gerontology and Geriatrics: a global agenda for clinical research and quality of care in nursing homes. *Journal of the American Medical Directors Association*. 12 (3) 185-189.

<sup>2</sup> Holmerová I, Koopmans R, Skela Savič B, Egervári A, Hermann B, Ruseckiene R, Tolson D. (2012) Advancing Long Term Care; Central European Perspectives. *JAMDA* 13 (7) 578-580

<sup>3</sup> Tolson D, Holmerova I, Macrae R, Waugh A, Hvalic-Touzery S, de Abreu W, Lillo Crespo M, Merta A, Hanson E. (2017) Improving Advanced Dementia Care an Interprofessional Learning Framework *JAMDA*  
<http://dx.doi.org/10.1016/j.jamda.2017.03.014>

Currently there are an estimated 50 million people worldwide with dementia, 5.4 million in Europe. By 2040, numbers of people with dementia living in Western Europe will double and the numbers in Eastern Europe will treble. It is difficult to obtain accurate numbers of how many nursing home residents have dementia, as not all have a diagnosis and statistical reporting methods differ across regions. One of the few UK studies that included clinical assessment found that almost 90% of Scottish care home residents have dementia of whom 35% have advanced dementia<sup>4</sup>.

Dementia is caused by illnesses such as Alzheimer's disease, which are neuro progressive and terminal. Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia together account for approximately 80% of dementias. The World Health Organization and Alzheimer's disease International have described dementia as a public health priority.

Dementia affects memory, thinking, orientation, language and other higher cortical functions of the brain, and for some is associated with changes in emotional control and social behavior. In the early stages of dementia, it is possible for people to live relatively independent lives but as the underlying illness progresses the complexity of healthcare need and dependency for the fundamentals of care, life and living increase. This makes dependency on others likely and when family based caring is no longer an option admission to a care facility becomes inevitable.

### Rights Based Care

The Glasgow Declaration <https://www.alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration-2014>, supported by delegates from 26 European Alzheimer organisations, recognises the right of individuals to high-quality care throughout their illness. The World Health Organisation global dementia action plan (2017-2025) reinforces that all care for people with dementia should be consistent with the Convention on the Rights of Persons with Disabilities. It follows that approaches to advanced dementia care within nursing home practice should be rights based<sup>5</sup>.

### The Palliare Project

The *Palliare* Project funded by the EU Erasmus+ Higher Education programme <https://www.erasmusplus.org.uk> was completed between 2014-2017. The first aim was to understand and describe best practice for advanced dementia care and to tease out the disciplinary knowledge and contribution. The second aim was to use this information to develop a learning framework and resources to equip the European qualified health and social care workforce to transform advanced dementia care to promote best practice. This involved a literature review, policy review, in depth case studies, an education gap analysis and consensus methods to develop a best practice framework to inform practitioner education. For brevity, the project is selectively reported, as it is not possible to report on all of the findings here.

The literature review explains how people with advanced dementia can live for months and sometimes years before end of life care is appropriate. However, much of the published research is preoccupied with death and dying and there are surprisingly few studies focussed on other aspects of advanced dementia care<sup>6</sup>. The review called for a new narrative and positive approaches to practice in all settings including nursing homes. Hence, the term *Palliare*, meaning to cloak in support, chosen to make a distinction between palliative care with its roots in non-dementia specific palliation and end of life care. Furthermore, it highlighted the opportunity to reform approaches to care with a focus on supporting people, including family carers, affected by advanced dementia to live the best life possible.

<sup>4</sup> Lithgow IS, Graham J.A. and Browne D. (2011) Estimating the Prevalence of Dementia: Cognitive Screening in Glasgow Nursing Homes. *International Journal of Geriatric Psychiatry*, 27, pp. 785-791.

<sup>5</sup> World Health Organization (2017) *Global action plan on the public health response to dementia 2017-2025*. World Health Organization ISBN: 978-92-4-151348-7

<sup>6</sup> Hanson E, Hellstrom A, Sandvide A, Jackson GA, Macrae, R, Waugh A, Abreu W, Tolson, D. (2016). The extended palliative phase of dementia – an integrative literature review. *Dementia* DOI: 10.1177/1471301216659797.

Case studies illustrated care at its worst as institutional ‘warehousing’ and at best as providing sanctuaries and safe Haven<sup>7</sup>. Dementia education was lacking in most countries and only Scotland was found to have a national workforce development framework<sup>8</sup>.

### Learning Framework for Best Practice

The development of the *Palliare* Best Practice Statement was consultative, drawing upon a wide range of evidence and consultative feedback cycles to ensure that people with dementia, family carers and a wide group of professional stakeholders had opportunity to comment. This included a consensus conference in Prague June 2015, and working with local, national and finally European Alzheimer and carer organisations. The Best Practice Statement, which is offered as a learning framework for practice is divided into six sections covering:

- 1: Protecting rights, promoting dignity and inclusion
- 2: Future planning for advanced dementia
- 3: Managing symptoms and keeping well
- 4: Living the best life possible
- 5: Support for family and friends
- 6: Advancing Dementia *Palliare* practice<sup>9</sup>.

Each section contains a table corresponding to the ‘what, why and how’ of best practice. ‘What’ summarises the content and the role of the professional. ‘Why’ expands on the reason for the statement. ‘How’ demonstrates how the statement can be achieved, highlighting the underpinning philosophy of the statement and explicit skill requirements to achieve best practice. One of the merits of the new *Palliare* narrative is that it reveals the expert knowledge and practical know-how required to deliver good quality advanced dementia care. It also recognises the roles that individuals and teams play and the challenges faced to champion change.

### Conclusion

Practice education, leadership, status raising and research, were identified by IAGG to be the cornerstones for the global nursing home development agenda. The *Palliare* educational framework challenges the lack of advanced dementia practice-based education and undervaluing of knowledge and skills required for advanced dementia care. It is an informative tool for nursing home leaders and reformers, who believe that people with advanced dementia deserve compassionate evidence informed care, delivered by confident practitioners. Implementation of best practice and the explicit valuing of the complexity of advanced dementia care will serve to raise the status of nursing home practice and improve the experience of care of many who are living with advanced dementia

<sup>7</sup> Lillo-Crespo M., Riquelme Galindo J, Macrae R., Abreu W, Hanson E, Holmerova I, Cabanero M, Ferrer R, Tolson, D (2018) Experiences of Advanced Dementia Care in seven European countries: Implications for Educating the Workforce. *Global Health Action*. DOI: <https://doi.org/10.1080/16549716.2018.1478686>

<sup>8</sup> Hvalič-Touzery S, BrigitaSkela-Savič B, Macrae R, Jack-Waugh A, Tolson D, Hellström A, de Abreu W, Pesjak K (2018) The provision of accredited higher education on dementia in six European countries: An exploratory study Volume 60, Pages 161-169://doi.org/10.1016/j.nedt.2017.10.010 <https://doi.org/10.1016/j.nedt.2017.10.010>

<sup>9</sup> Holmerová, Waugh A, Macrae R, Sandvide., Hansen E, Jackson G, Watchman K, Tolson D. (2016). *Dementia Palliare Best Practice Statement*, University of the West of Scotland. DOI: 10.13140/RG.2.1.3382.7446.

Jayne Murphy RN, BSc(Hons), MA, SFHEA, QN

## Decision-making on behalf of people with advanced dementia



Jayne Murphy started her NHS career as a Health Care Assistant in the 1990s and continued on to undertake her registered nurse training at the University of Wolverhampton School of Health. She developed an affinity for community nursing and her first registered nurse post was a community staff nurse. As her career progressed she worked as a Specialist Practice District Nursing Team Leader and Community Matron, eventually moving into the role of Practice Education Facilitator to support the workforce in education and training. This is where she developed a special interest in dementia care and she took the opportunity to take on a project lead role for dementia. She joined the Community Nursing Team at the University of Wolverhampton in April 2014 where, as well as teaching on specialist practice and prescribing programmes, she was able to continue with her interest in dementia, joining the University Centre for Applied Research and Education (CARE) and supporting their work in promoting dementia care throughout the University.

### Introduction

Dementia is a term used to describe the symptoms experienced by a condition, illness or syndrome that results in physical damage to areas of the brain. The progression of the symptoms and deterioration in mental function differs in individuals and disease processes, but the outcome is consistent; a decline in physical and mental functions. Over time, it is assumed that the person with dementia will become progressively more dependent on others for all aspects of his or her care (O'Connor and Purves 2009). There is now much more knowledge about the damaged brain that causes the symptoms of dementia but also about the abilities that remain, despite the loss of cognition; this poses a challenge to past ideas of dementia and raises questions as to how people with dementia are regarded and respected (Nuffield Council on Bioethics 2009).

This article aims to explore the complexities of decision-making on behalf of a person with advanced dementia. Specific ethical issues will be presented alongside the challenges associated with decision-making on behalf of others; the strengths and the potential pitfalls. With specific reference to the UK legislation to support decision-making for adults lacking capacity (primarily the legislation from England and Wales), important considerations will be presented that highlight the professional obligations of the healthcare workforce.

### Ethical aspects of decision-making

Dementia often raises specific ethical issues because of the kind of difficulties it creates. Loss of control over both self and the environment is an inherent feature of all forms of dementia, which may well affect the goals of care preferred by that individual (Gillick 2012). People with advanced dementia are likely to be so cognitively compromised that they are unable to make an informed choice about healthcare treatments. In cases such as this, healthcare decisions are subsequently made by others on their behalf.

The decline in mental capacity and ability to function independently is distressing for the person and potential for conflicts of interest between the person with dementia and their carer generates ethical difficulties (Nuffield Council on Bioethics 2009). When ill, people often experience greater dependency, and with it, a greater likelihood that they will have their interests and values overridden by others. For example, there is a significant risk of paternalism where healthcare professionals are tempted to substitute their own judgment for that of a 'patient', particularly when they feel that they have a better insight into that person's medical needs than the person themselves and they seek to ensure the best medical outcome (Sherwin and Winsby 2010). Questions as to whether the person should receive life-sustaining interventions, particularly nutritional support, antibiotics, and cardiopulmonary resuscitation frequently arise while the person with advanced dementia is still conscious and before they are terminally ill (Dresser and Whitehouse 1994). Ethical practice

demands attention to those influential variables that may diminish, alter or enhance a person's capacity (Bowman 2008). It is therefore important to consider ideas that enhance decision-making processes and improve potential outcomes for people with advanced dementia, even if those outcomes dictate a poor prognosis.

#### Enhancing decision-making

Once decision-making ability is affected, the person with dementia is highly reliant on others to sustain their autonomous rights or to substitute that right with a decision that will have an outcome that they would choose for themselves if they retained that power. Legislative statutes, advisory policy or practice guidance exists in many countries regarding decision-making for incapacitated people and there is much to learn from those countries that do it well. In the UK this legislation is provided by the Mental Capacity Act (MCA) (2005) in England and Wales, Adults with Incapacity Act (2000) in Scotland and Mental Capacity Act (2016) in Northern Ireland. This article focuses on the legislation of England and Wales; MCA (2005), which gives incapacitated people the right to be involved in the decision-making process and deems any decision made on their behalf to be in their best-interests, should they be unable to engage in the decision itself (Brazier and Cave 2009). The MCA (2005) seeks to provide a secure framework in which all parties concerned can make best-interests decisions about care for people who may lack capacity (Ryan et al 2009).

Healthcare professionals generally have a level of knowledge and expertise that puts them in the best position to make rational decisions about the impact that specific actions or interventions will have. For instance, healthcare professionals have enough experience to predict the anticipated outcomes of treatments and whether the person will benefit from these interventions. Where treatments are deemed futile, healthcare professionals generally have established knowledge to weigh up the risk and benefit ratio. Society usually places trust in healthcare professionals to process the facts and present the information to be able to make an informed decision. In the absence of the ability to make the informed decision, society generally accepts that the professional accountability of the healthcare professionals lead them to take the course of action that is most appropriate to the situation and for the person concerned. Wrigley (2007) supports this view when he suggests that assessment of what constitutes best-interests of the person is still a clinical matter, with the medical team in a position to decide whether treatment is in a person's best-interests, that the general consensus of decision-making tips the balance towards a professional, paternalistic judgment because professionals possess the specialist knowledge that determines the initial choice of treatment options. It could be suggested then, that healthcare professionals, when acting within their individual codes of practice, automatically make decisions that are person-centred and offer the best outcome for the person in their care. If this is the case, then there should be little criticism of practise related to the rights of people that lack capacity, including those living with advanced dementia. Unfortunately, there is significant criticism relating to infringements of rights and in the case of the MCA (2005) there is an alleged widespread failure to adhere to the Act (Wade and Kitzinger 2019).

#### Challenging decision-making

Healthcare professionals are duty bound to adhere to the MCA (2005), which stipulates the steps to take to ensure that best-interests are considered. However, there is the suggestion that the best-interests principles expose the person to risk; that even though the hypothetical 'reasonable person' is evaluated, preferences considered, and medical knowledge applied, the person may still have the values of the healthcare professional imposed upon them (Defanti et al 2007). The Mental Capacity Act: Code of Practice (COP) is linked to the legislation and recognises the challenges of defining what best-interests are; that every case and every decision is different and that the law cannot set out all the factors that need to be considered in working out someone's best-interests (HMSO 2005). Although the COP sets out some common factors that must always be considered when trying to work out someone's best-interests, this is a recognition of the inconsistency of the approach; that considerations need to be made but with specific attention to individual cases, as there is no guidance that will apply to all cases in all settings.

Although there is evidence to suggest that healthcare professionals possess the knowledge, skills and expertise to result in decision-making that best suits the situation and promotes the most appropriate outcome, there

are also schools of thought that lean towards the opinion that medically led decisions can cause harm to the person lacking capacity. A healthcare professional may evaluate a person's quality of life differently, and often as less desirable, compared to the person's own evaluation of his or her situation. Also, the healthcare professionals' decisions about the capacity of people may be influenced by their own emotions and attitudes (Braun et al 2009). Healthcare professionals may follow their own agenda when considering decision-making capacity of others; failing to afford people the autonomy they deserve. This opinion is supported further with research conducted by Boyle (2010) where people with dementia were deprived of opportunities for exercising self-determination even when they had capacity, when there was conflict between a person and their carers over admission to care facilities.

Though healthcare professionals may be accused of acting without contemplating the decision-making capacity of a person, it is difficult for them to satisfy their professional integrity, family preferences and the person's best-interests, as there are many influences and demands placed on them. With people who lack capacity, healthcare professionals are obliged to consider the rights of the person and balance this with the requests of the family, that may be in direct contrast to what they feel is medically reasonable. Although healthcare professionals are deemed to have the medical knowledge and expertise to influence decisions in the best-interests of the people that they care for, there are restrictions on their professional autonomy from the unending influences that they are obliged to consider.

### Recommendations

Although the legislation has been criticised in respect of its implementation and healthcare professionals' understanding, it deserves serious ethical attention (Hope, Slowther and Eccles 2009). Keeping the best interests of an individual at the centre of decision-making is a professional responsibility and the principles within the MCA ensure that this is the case if nine principles are followed (Regan and Sheehy 2016). These nine principles are:

1. Encourage the individual's participation.
2. Consult all those close to the individual.
3. Consider the individual's views, whether expressed verbally or in writing, including their feelings, religious beliefs and past habits.
4. Consider all circumstances, including emotional bonds and family obligations.
5. Avoid making assumptions.
6. Consider whether capacity will be regained in the future and whether this decision could be delayed until then.
7. Consider the potential decision the individual might have made if they still had capacity.
8. Consider whether the least restrictive option has been taken in making the decision.
9. If the decision is about life-sustaining treatment, ascertain that no one involved in the decision-making process has a desire to end the life of the individual and that no assumptions have been made about their quality of life.

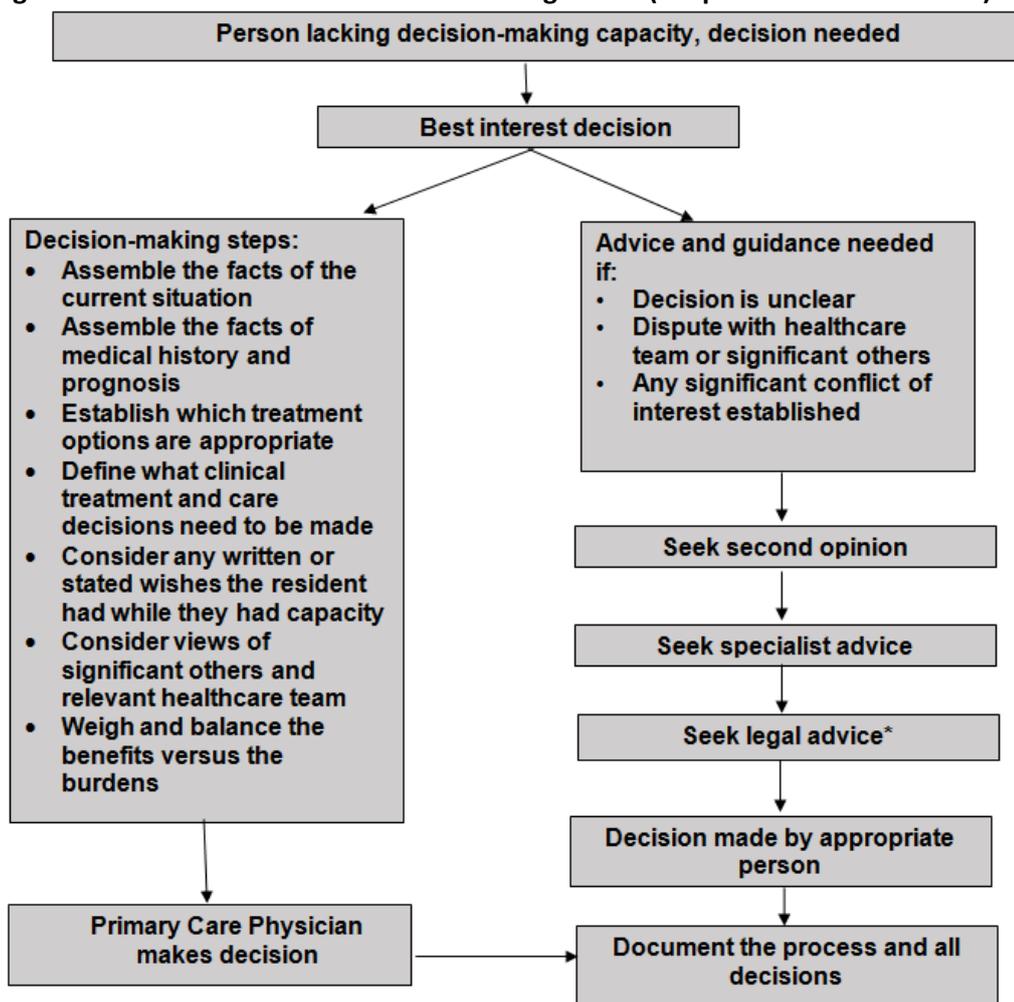
Hope, Slowther and Eccles (2009) recognise that the MCA and the associated guidance do not provide enough guidance to carers faced with difficult decisions regarding best interests. Martin (2015) suggests that a clinical decision-making model may assist staff with difficult dilemmas. Figure 1 is an adapted version of this model as the original version is based on a UK legal system. The recommendation is to take steps to reach a decision, including seeking advice from others with a vested interest in the person's wellbeing. These steps refer directly to the best-interests guidance from the UK legislation and recommend where the courts may need to intervene. If there is no court process, then legal advice may be appropriate, which may impact on who is appropriate to make the decision. This model identifies the primary care physician (GP in the UK) as the overall decision-maker but it is the process that is useful to bear in mind, rather than the responsibility of who makes the final decision. The main theme within most of the literature relating to best interests is the importance of making decisions that reflect the values and beliefs of the individual concerned and that carers have often developed skills in negotiating decisions with their partners as their capacity diminishes (Regan and Sheehy 2016). Therefore, seeking to establish the values and beliefs of the person and involving those who know the person best can only serve to promote person-centred decisions that best reflect what the individual may have

decided if capacity was not an issue. Despite the criticisms of the legislation, the aim is to encourage healthcare professionals to consider these factors when making decisions for people that lack the capacity to decide for themselves. If the guidance is applied with due regard, then the results should reflect the intention; person-centred outcomes of care despite the challenges associated with decision-making for others.

**Conclusion**

Current literature suggests that best-interest decisions are often clinically driven, professionals pick and choose when to involve family members and the principle is often used as a tool to justify safeguarding decisions (House of Lords Select Committee (HOLSC) 2014). Additionally, significant improvements in building knowledge and application of existing legislation are required to enhance people’s healthcare experience, particularly people living with dementia, who appear to be largely affected by questionable practice in relation to the legislation (HM Government 2014). Another large-scale research project exploring professional practices in best-interest decisions made since the introduction of the MCA (2005) was published in 2012 (Williams et al 2012). The report recommended that further research be carried out to understand better the different perspectives of those involved in best-interest decisions. There appears to be a lack of contemporary research that explores perspectives of best-interests, therefore it is timely to explore perspectives of healthcare professionals in relation to decision-making in the best-interests of people that lack the capacity to decide; including people living with advanced dementia. By exploring perspectives around ethical issues, considerations of what enhances decision-making and what challenges decision-making, it is possible to identify improvements to the process, promoting knowledge-sharing in respect of these ethical dilemmas. This has the potential to inform practice for the better, improving experience for people living with dementia, their carers and the healthcare workforce involved in their care.

**Figure 1: Best interest clinical decision-making model (adapted from Martin 2016)**



## REFERENCES

- Adults with Incapacity Act Scotland (2000) The Stationery Office: Edinburgh.
- Bowman, D. (2008) in Stoppe, G. (Ed) *Competence Assessment in Dementia*. Springer Wein. New York
- Boyle, G. (2008) The Mental Capacity Act 2005: promoting the citizenship of people with dementia? *Health and Social Care in the Community*. 16 (5). pp. 529 – 537.
- Braun, M. et al (2009) Are Clinicians Ever Biased in Their Judgments of the Capacity of Older Adults to Make Medical Decisions? *Journal of the American Society on Aging*. 33 (1) pp. 78 – 81.
- Brazier, M. Cave, E. (2011) *Medicine, Patients and the Law*. (5th Edition) Penguin. London.
- Defanti, C. et al (2007) Ethical questions in the treatment of subjects with dementia. Part I. Respecting autonomy: awareness, competence and behavioural disorders. *Neurological Sciences*. 28 pp. 216 – 231.
- Dresser, R. (1995) Dworkin on Dementia. *The Hastings Center Report*. 25 (6) pp. 32 – 38.
- Gillick, M. (2012) *Doing the Right Thing: A Geriatrician's Perspective on Medical Care for the Person with Advanced Dementia*. *Journal of Law, Medicine & Ethics*. Spring Edition. pp 51 – 56.
- HM Government (2014) *Valuing every voice, respecting every right: Making the case for the Mental Capacity Act*. The Government's response to the House of Lords Select Committee Report on the Mental Capacity Act 2005. Crown Copyright: London.
- Hope, T. Slowther, A. Eccles, J. (2009) Best interests, dementia and the Mental Capacity Act (2005). *Journal of Medical Ethics*. 35 pp: 733 - 738
- House of Lords Select Committee (2014) *Mental Capacity Act 2005: post-legislative scrutiny*. The Stationery Office: London.
- Martin, S. (2015) Best interest clinical decision making for care home residents with advanced dementia. *British Journal of General Practice*. 65 (637) pp: 427-428.
- Mental Capacity Act (2005) (c.9) HMSO. London.
- Mental Capacity Act Northern Ireland (2016) The Stationery Office. Norwich.
- Mental Capacity Act (2005) Code of Practice. HMSO. London.
- Nuffield Council on Bioethics (2009) *Dementia: ethical issues*. Cambridge Publishers Ltd. Cambridge.
- O'Connor, D. Purves, B. (2009) (Eds) *Decision-Making, Personhood and Dementia*. Exploring the Interface. Jessica Kingsley Publishers. London.
- Regan, A. Sheehy, C. (2016) Understanding mental capacity law and making best-interests decisions. *Nursing Standard*. 31 (14) pp: 54 – 62.
- Ryan, T. Ingleton, C. Gardiner, C. Nolan, M. Gott, M. (2009) Supporting people who have dementia to die with dignity. *Nursing Older People*. 21 (5) pp. 18 – 23.
- Sherwin, S. Winsby, M. (2010) A relational perspective on autonomy for older adults residing in nursing homes. *Health Expectations*. 14 pp.182 – 190.
- Wade, D. Kitzinger, C. (2019) Making healthcare decisions in a person's best interests when they lack capacity: clinical guidance based on a review of evidence. *Rehabilitation in Practice*. 00 (0)pp: 1 – 15.
- Williams, V. Boyle, M. Jepson, M. Swift, P. Williamson, T. Heslop, P. (2012) *Making Best Interests Decisions: people and processes*. Mental Health Foundation: London.
- Wrigley, A. (2007) Proxy consent: moral authority misconceived. *Journal of Medical Ethics*. 33 pp:527 – 531.

*Ewa Kądzalska PhD*

## Frailty syndrome as one of the great geriatric problems.

---

*Academic tutor, since 2002 at the Medical University of Warsaw and since 2011 – in the Józef Piłsudski University of Physical Education in Warsaw. Since 2015 she has been the Assistant Professor at the Geriatrics Department of the National Institute of Geriatrics, Rheumatology and Rehabilitation, a specialist in the geriatric and palliative care and clinical nutrition. Since 2018 she has been the state consultant in geriatric nursing. She has been involved in the Geriatrics and Senior Support Task Force operating by the Polish State Development Council operating by the President of the Republic of Poland as well as in the project consisting in the liaison with the World Bank in modelling co-ordinated care in geriatrics. Authoress of scientific and research dissertations and publications in nursing and management. Since 2016 she has been actively involved in the international projects of the European Union, such as: JA ADVANTAGE and CHRODIS PLUS representing the partner establishment – the National Institute of Geriatrics, Rheumatology and Rehabilitation in Warsaw.*

---

### **Frailty syndrome as one of the great geriatric problems. Managing Frailty. A comprehensive approach to promote a disability-free advanced age in Europe: the ADVANTAGE initiative.**

The Frailty Syndrome is the most problematic expression of people's old age. This syndrome develops as a consequence of the cumulated weakening of numerous physiological processes throughout life (including neuro-endocrine, hormonal and immunological regulation). Among the factors that are important in the etiopathogenesis of the Frailty Syndrome, there are biological factors (such as: inflammatory, hormonal), clinical ones (sarcopenia, osteoporosis) and social ones (social isolation, poor financial standing).

As a result of the deteriorated functioning of an elderly person in the biological as well as psycho and social sphere, even some minor stressors lead to the unproportionate change of the health condition which is usually expressed by the tendency to fall, hallucinations and other unfavourable consequences. In the implemented project, we have adopted the definition of the *Frailty Syndrome* which had been published in the World Health Organisation in 2015 where the Frailty Syndrome is a “*progressive, age-related decline of physiological systems that results in decreased reserves of intrinsic capacity which confers extreme vulnerability to stressors and increases the risk of a range of adverse health outcomes*” (WHO. World Report on Ageing and Health 2015). Following the estimates obtained from the countries where screening tests and Frailty Syndrome diagnostics are held on regular basis, it is assumed that **in Europe 17% of the elderly (65+) satisfy the requirements of the Frailty Syndrome while 44% approach their satisfaction (2012)**. The advanced age is the risk factor for the Frailty Syndrome.

In the diagnostics of the Frailty Syndrome, the following multi-aspect diagnoses criteria are used: **clinical ones** – at least 3 criteria to be satisfied out of the following: decline of the body weight more than 5 kg within 12 months, weakening muscle strength, exhaustion, slower walking, decreased physical activity (Fried et al.); **functional ones** – loss of vital functions, limited activity (Gobbens et al.); **multi-dimensional ones** – deficit of physical functions, disturbed cognitive processes and psycho and social functioning (Rockwood et al.).

The simple, validated tests, such as: Prisma 7, Gait Speed Test, Timed Up and Go Test or Clinical Frailty Scale allowing for quick screening tests during the check-up at the family doctor or GP are most practically used in the diagnostics.

The JA ADVANTAGE project in which Poland is involved is a common action of 22 EU Member States and 35 establishments.

The project objectives are as follows: building awareness of the risk and dissemination of the Frailty Syndrome in the society among the interested parties, especially among the health policy decision-makers; strengthening liaison with stakeholders, suggesting common European strategy: from screening tests, through modern diagnostics and assessment of the progress stage of the Frailty Syndrome, to the selection of the behaviour model; promoting important and permanent changes in the organisation as well as the implementation of health and social care in Europe.

Until today, the first of the reports has been developed, that is, *Layman Report of the State of the Art Report on Frailty Prevention and Management*, where experts elaborate on the preliminary recommendations on how to prevent the Frailty Syndrome, including recommendations emphasising the significance of actions such as:

- ✓ tailor-made patient's assessment and appropriate planning of the individual care,
- ✓ focus on *case management*,
- ✓ co-ordination of home care and community support as part of the care continuity to be supported by partner-based, close liaison between the *case manager* and the family doctor,
- ✓ orientation towards multi-dimensionality of the care – interventions in physical, cognitive, social and functional dimension to be offered by an interdisciplinary team both in hospital and in the habitat of an elderly,
- ✓ adoption of clear rules and procedures pertaining to the qualification for the care process as well as efficient care management, always in line with the changing needs,
- ✓ using electronic informational tools and technologies in order to implement optimal solutions in the integrated care.

The next reports, such as: Frailty Prevention Approach and publications presenting the status of project works are being developed. The up-to-date information will be announced regularly by the research team at [www.spartanska.pl](http://www.spartanska.pl), [www.advantageja.eu](http://www.advantageja.eu) as well as at [zespolkruchosci.pl](http://zespolkruchosci.pl) Internet platform, among others.

*Justyna Mazurek PhD, Dorota Szcześniak PhD*

## Decision-making on behalf of people with advanced dementia



*Educated as both a doctor specializing in medical rehabilitation and as a physiotherapist, Justyna works as Assistant Professor in the faculty and Department of Rehabilitation Medicine at Wrocław Medical University and as a physician in the Rehabilitation Unit in the Jadwigi Śląska Hospital in Trzebnica. Her main interests concern a holistic approach to rehabilitation, geriatrics, neurology, and psychiatry. Justyna is currently carrying out research on the needs of seniors, broadly construed, including the needs of seniors living with dementia.*

Can institutional support replace a home? Meeting Centre Support Programme (MCSP) for people with dementia and carers it is an example of a well-organized practical solution that has been successful among its community dwelling users. MCSP originally developed in the Netherlands was successful adapted and implemented in Italy, Poland and the United Kingdom under the JPND-funded MEETINGDEM project (2014-2017).

MCSP is an evidence and theory based solution that has the potential of systemic dissemination and implementation. It provides activities and person-oriented interventions for people with dementia, information meetings and discussion groups for their carers, and individual consultations and plenary (social) centre meetings for both with the main scope to support people in dealing with the changes dementia brings in their lives.

According to the obtained results positive effects were found among people living with dementia in several quality of life aspects such as: feelings of belonging, positive affect and self - esteem. The attendance to MCSP was high and participants, people with dementia as well as carers, were highly satisfied with the program. User Evaluation of Meeting Centre participants consisted of both qualitative and quantitative methods in all three countries. Carers admitted that they feel less burden than before they had started participation in MC. Focus group analysis emphasized that people with dementia improved their ability to deal with adaptive tasks described in the Adaptation-Coping Model, originally developed by Dröes, in three areas: reactivation, resocialisation and improvement of emotional functioning. People with dementia reported improvement in quality of life, motivation and ability to participate in everyday activities. The satisfaction from relationships between them and family members increased as well. Carers highlighted the improvement of mood and level of motivation of their closest ones. They also indicated the importance of emotional and informative support they received in MC.

In Poland also experienced unmet needs by people diagnosed with dementia and by their carers were explored and compared using the Camberwell Assessment of Need for the Elderly (CANE). The CANE is the first tool designed to assess a wide range of needs of older people and can be used in persons who are mentally ill, and who reside in health and social care centers and in primary care facilities. Twenty-four needs areas are covered. Each area is divided into five sections. The CANE assesses the physical needs (physical health, drugs, mobility/falls, self-care, incontinence, and eyesight/ hearing/communication), psychological needs (behavior, psychotic symptoms, alcohol, accidental and deliberate self-harm, psychological distress and memory), environmental needs (managing money, household activities, caring for another, and money), and social needs (company, intimate relationship, daytime activities, information on condition and abuse/neglect).

A pre/post-test control group design was used for comparing outcomes for people with dementia and family carers attending the MCSP or a Usual Care (UC) at two time points, at baseline and after 6 months. Based on the opinions of people with dementia and informal carers the unmet needs were reduced considerably in the participants attending the MCs compared to those receiving UC, providing evidence that the participants from the new form of support, MCSP, could be benefited from it with regard to fulfilling unmet needs within an intervention period of only 6 months. Moreover, an increase in formal support both reported by the persons with dementia and their carers was found to a much greater extent in the MCSP, than in the UC groups.

The MCSP may, therefore, be seen as a good example of an integrated post-diagnostic psychosocial support for people with mild-to-moderate dementia and their carers. The MCSP might constitute an important part of the post-diagnostic support process, which makes it possible to intervene in a timely manner and to improve the access of people with dementia and dwelling in the community together with their carers to the support and care that is available for them.

User evaluation of MCSP showed that the Dutch model helps people living with dementia and their informal carers in their capacity to cope with everyday activities and challenges cause by dementia. The support provided by MCSP is adjusted to participants' wishes and needs which has a visible impact on their life's quality.

The study shows that MCSP is transferable across countries, well accepted by its users, and has quality of life and mental health benefits for people with dementia and carers against reasonable additional costs. Dissemination of MCSP in Europe and beyond is recommended.

## Piotr Krakowiak PhD

### Compassionate Communities as an opportunity to integrate care for people with dementia and their relatives in Poland and Eastern Europe.

---

*Piotr Krakowiak works currently as Professor of UMK University in Torun, Poland being Head of the Department of Social Work and also National Chaplain of Hospices in Poland. He has lengthy career in hospice-palliative care as chaplain, psychologist, volunteers' coordinator, managing director of Gdansk Hospice, and Hospice Foundation Poland, before moving into a teaching & research career. His Research interests focus on using mixed methods to explore end-of-life care in different settings, from social work through spirituality & bereavement, as well as various aspects of volunteering and community involvement. He is currently leading research regarding prisoners as palliative care volunteers in Poland. Living and working in Scotland since 2016 he is studying concept of Compassionate Communities in the UK and issues of migrant workers from Poland and other EU countries.*

---

Care and empathic compassion are crucial for the families of seriously ill people. Families most often help the caring team during illness, knowing that the situation is temporary and that their loved one will soon "feel better". For families caring for loved ones with dementia, however, this situation is irreversible and therefore very different from many other diseases. Also the situation of family caregivers is difficult and even impossible to compare, both due to the long duration of the disease, its management, as well as the often negative social perception regarding dementia diseases.

Dementia affects not only the sick, but also imposes a significant emotional burden on carers at subsequent stages of the disease. Families are reluctant to accept outside help, while most of them are busy family members who strive to provide the best care possible. Professional caregivers can see how much family caregivers can be exhausted, overwhelmed and how much help is needed. They expect support from the team and the environment. Families adapting to the new reality need help at different stages of care, and such help can be provided by empathic communities in the local environment.

Professor Allan Kellehear wrote about the idea of 'compassionate communities: Today (we have) a polarized approach to care for the elderly, chronically and terminally ill, as well as people in mourning. (...) Local communities are able to do more to support families, entities of health services and social assistance, to bring practical solutions. The commitment of empathic local communities to care at the end of life is an urgent need for not only care institutions but the whole of society to show active concern for people at the end of life and their loved ones. These words particularly apply to people with dementia and their relatives, especially those caring at home, but also in care institutions.

A compassionate community can be described as a community that identifies and seeks to include vulnerable people living within its borders and marginalized in the local community. It is primarily about activities for the active inclusion and integration of various groups of people marginalized by diseases or other circumstances. Communities, which, compassionately try to take into account the needs of groups living on the margins of the local community, through practical education and being sensitive to their life needs, are already operating in many countries on several continents. Areas of their practical activities are dementia patients and their relatives.

Key principles related to the preparation and creation of an empathic community within the local community are: undertaking grass-roots initiatives; consensus development; openness to cooperation and partnerships; listening to the local community, especially people at risk of marginalization; the use of tools to facilitate the exchange of ideas by all through questionnaires and focus groups. The lecture will show in a practical way the benefits of keeping local communities aware of important social problems, and dementia diseases are certainly among them increasingly. More on compassionate communities at: [www.phpci.info](http://www.phpci.info); [charterforcompassion.org/communities](http://charterforcompassion.org/communities); [dailyaring.com](http://dailyaring.com). Further reading: K. Wegleitner, K. Heimerl & A. Kellehear (eds) (2016) *Compassionate Communities: Case studies from Britain and Europe*. Routledge.