



GLOBAL ACTION ON PERSONHOOD IN DEMENTIA

The International Person Centred Values Practice Network for Dementia Care

**By delivering skilled care we can prevent the excess disabilities,
distress and harm caused by poor quality care.**

**Getting this right will lead to the recognition of the needs of people
living with dementia, an end to inappropriate antipsychotic
prescribing and use of physical restraint, and greater inclusiveness of
people with dementia in society world-wide**

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All core group members of GAP in Dementia have contributed along with members of the Association for Dementia Studies at the University of Worcester.

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The Aims of GAP in Dementia

GAP in Dementia is an international network of expert practitioners, researchers, academics, people living with dementia and family care-givers who have in-depth understanding of person-centred approaches to care world-wide. The aim of GAP will be to promote the fact that personhood matters in dementia and that unless action is taken then the psychological, emotional and social needs of people living with dementia are unmet. The overarching aim of GAP is to spread best practice world-wide. Actions will include

- To share good practice globally, what “good looks like” across the diversity of contexts and situations in which people with dementia need skilled care
- To develop easy to access channels of communication for the dissemination of research, education and practice development programmes world wide
- To identify person centred care competencies, skills and knowledge across countries.
- To share ways of improving skilled dementia care practice that are effective in low and middle income countries as well as in high income countries; in rural communities and in urban communities.
- To provide international placements and development schemes for innovators.

Call to action

We call for 6 actions that all professionals, researchers and communities of care can sign up to world-wide to promote the personhood of those living with dementia:

- Support people with dementia to be empowered to lead their own life to take control
- Help the person, their family , friends and community to deal with the consequences of (their) dementia
- Actively seek the standpoint of the person living with dementia
- Help people to remain connected to family, friends and community
- Reduce excess disabilities through the elimination of care practice associated with Malignant Social Psychology and to promote Positive Person Work
- Recognise that supporting people with the complexity of living with dementia requires specific skills from care-givers and professionals

Why GAP?

GLOBAL ACTION

Many people world-wide who have dementia or who have family members or friends with dementia feel overwhelmed. There is a lot of knowledge about how to provide skilled care, support and assistance but there is a disconnect to this getting into practice. This leads to unnecessary suffering for people living with dementia, their families and staff who provide support. This is a global challenge and demands a global response in the same way as finding a cure for dementia. No single country has found a solution for how we manage this on a large scale although many have islands of good practice.

PERSONHOOD

Although the many contexts and interventions that are involved in skilled care will vary worldwide we believe that the universal challenge that faces people living with dementia is that their personhood is undermined by poor quality care and support. Thus we have chosen this term on which to focus our action. By focussing on personhood our aspiration is to go much further than the prevention of excess disabilities and distress. By ensuring that people can preserve their personhood and have the opportunity to remain in relationship with their environment they can maintain independence, autonomy, personal growth, joy, pleasure, meaningful activity, life satisfaction, fulfilment and a sense of well-being.

GAP

A gap is a space between things and people or between where we are and where we wish or need to be. The decline in cognitive powers that come with dementia (particularly in more advanced dementia) creates a gap between people. Cognitive impairment also means that people living with dementia find it increasingly difficult to reach out to those they need help from to bridge the gap. If the person can only express need through the sorts of reactions that are labelled as BPSD then this widens the gap between the person living with dementia and those who could help even further. We can support the personhood of people living with dementia by reaching into that gap and providing support that is tailored to the needs and wishes of the individual. By bridging the gap we recognise that we are all connected to each other, that there is no US and THEM. There is just US.

Filling the gap in the G7 Global Action

The impetus for this group was born at the G7 Dementia Action legacy event in Tokyo on Prevention and Careⁱ. This was an inspirational event and an important step in recognising that dementia is a global issue that demands a global solution. G8/7 action on dementia has challenged us to find a disease modifying drug for dementia by 2025. This is a laudable aim. But there are many things that all of us can do right now that would help restore the peace of mind for many of those who are struggling with cognitive loss. The World Health Organisation First Ministerial Action on Defeating Dementia Call to Action in March 2015 that was signed by 80 countries world-wide recognised this. This called for continuous improvements to be made for the care of people living with dementia and support for their caregivers.

The members of GAP in dementia propose

By delivering skilled care we can prevent the excess disabilities, distress and harm caused by poor quality care.

Getting this right would mean recognition of the needs of people living with dementia, an end to inappropriate antipsychotic prescribing and use of physical restraint, and greater inclusiveness of people with dementia in society world-wide

There is much that can be done to alleviate the distress of those living with cognitive loss both now and into the future. The experience of living with dementia is underpinned by a complex interplay of many factors (neurological, physiological, psychological, and societal). The need for skilled care will not be eliminated. The need to focus on the many things we can all do right now remains. Even if pharmaceuticals one day are able to cure or slow down the many (over 100) diseases that result in dementia, the process of being diagnosed and being treated – just like that for cancer – will require high standards of care, now and into the future.

The behaviours and psychological consequences of poor quality care are often referred collectively as BPSD (Behavioural and Psychological Symptoms of Dementia). BPSD is an umbrella term for the secondary symptoms of dementia such as agitation, hallucinations, delusions, depression, anxiety, aggression, vocalisations, etc., which are very common in dementia. These are the problems that can lead to people being inappropriately prescribed anti-psychotic medication or being physically restrained or sedated. These are the types of behaviour listed on the NPI (Neuro Psychiatric Inventory) and sometimes also called neuropsychiatric symptoms, challenging behaviours, distress behaviours or responsive behaviours.

These behaviours are often interpreted as being an inherent part of the dementia itself. However, the majority of these problems are the result of untreated delirium, untreated pain, poor nutrition and hydration, boredom, unmet emotional needs, the care provider's lack of understanding of cognitive capacity, difficulties dealing with the consequences of dementia, poor communication, malignant social psychology, lack of knowledge about the person's history, and poor general care.

Many of these problems occur through lack of understanding of what it is like to be a person living with dementia. Understanding these challenges is not something that is taught to any great extent on professional education courses. There is often a gap in the experience between those living with dementia and those providing care and support. This gap widens as the dementia progresses. Professionals seek to "manage" behaviour without really understanding why it is occurring. Indeed, even the term BPSD makes high levels of distress sound an inevitable consequence of dementia. Indeed, it may be better not to use this general term in care practice as it often does not help to understand what is causing the person to experience such problems.

This is the arena in which skilled care really counts and really makes a difference. By understanding why problems are occurring and by providing

supportive interactions where people are met with warmth, inclusion, respect and empathy people will feel less confused, and more relaxed, socially confident and joyful. This will directly reverse or decrease those feelings underpinning the occurrence of mood and behaviour changes. This does not mean that the dementia has gone away BUT it does mean that the person feels less like they are losing their mind.

In order to get person centred care into practice the whole service organisation needs to align itself to this vision. Simple training for front-line care workers is not enough on its own.

The Gender Issue

Dementia impacts on the lives of women more than men worldwide in terms of people who live with dementia and of those who provide care. Those of us in GAP have delivered lectures & workshops worldwide on the provision of skilled care in all of the G7 countries and beyond. The audience that come to listen are primarily female. They are hungry for knowledge to deliver their care in a better way. They take this knowledge and transform lives, often quietly. The main providers of skilled care are female (with significant notable exceptions). Their voices and skillset go often go unheard.

How GAP will operate

The initial core membership was formed in January 2015 following a series of emails initiated by Dawn Brooker. The core group of 50 grew from professional networks of those with expertise in skilled care and support either in practice, research or being affected by dementia in their own lives. All the core group have a demonstrated contribution to improving the quality of person centred care for people living with dementia on a large scale. They also have the aptitude to work cooperatively and collegially recognising the value of learning from international practice. GAP also includes a number of people living with dementia and family care-givers

who are active in the field of promoting the rights of people living with dementia.

It is anticipated that, from this core membership, a number of key actions will be developed with various combinations of members leading on different aspects of work going forwards. The core group is not intended to be exclusive. New people are welcome. We envisage building an affiliates group and national programmes whereby people can sign up to the aims and share best practice. Key measures of success will be developed.

GAP is about gathering skills and talents to these aims. Professional qualifications are less important than proven track-record in the field. Our membership includes people with expertise from professional practice, from research and through personal experience. Our aim is to be inclusive of those with energy and skills in order to establish an international presence.

¹ The original group grew out of a long association between many practitioners implementing PCC in dementia care around the world. Its inaugural official beginning was agreed in a meeting with delegates from UK, Japan, Netherlands, Belgium, Italy, Norway, Sweden, Australia, Portugal, Singapore, Spain, Denmark, Canada and USA in Aarun, Switzerland in October 6th, 2014.