



THE ALZHEIMER
SOCIETY *of* IRELAND

Submission

Towards A Restraint Free Environment in Nursing Homes

April 2010

1. Introduction

“If we spent as much time on trying to understand behaviour as we spend trying to manage or control it, we might discover that what lies behind it is a genuine attempt to communicate.”

Goldsmith, M. (1996) Slow down and listen to their voices, Journal of Dementia Care 4(4) 24-25

The Alzheimer Society of Ireland welcomes the opportunity to make a submission on the development of a policy on a restraint free environment in nursing home care. As an organisation committed to advocacy for people living with dementia, the Alzheimer Society of Ireland is keen to influence policy and services that impact on the lives of people with dementia and their carers. (For more information on the Alzheimer Society of Ireland please see www.alzheimer.ie)

Given the role that nursing homes play in long term dementia care and predicted increases in the proportion of people with dementia in the Irish population, there is a compelling need to address this area and ensure that standards are met to ensure people who live there enjoy a decent quality of life. The Alzheimer Society welcomes the recent development of the HIQA National Quality Standards for Residential Care Settings for Older People in Ireland. They are the beginning of a road map for those in residential care to enable them to live a decent quality of life.

The Alzheimer Society is aware that this is a generic policy development which relates to all those who are living in long term care. However, there is speculation that approximately one third to one half of all residents in long term care have dementia (O’Shea, 1999, p.93, citing Ineichen, 1999) Therefore, this policy will have a major positive impact on a significant number of people with dementia.

People with dementia are often identified as ‘problematic’ in long term care and are often the subjects of restraint given that they are perceived as having ‘behaviours that challenge’. The Alzheimer Society is also aware of the highly complex nature of the issue of restraint and its direct correlation to elder abuse in particular.

The approach that has been taken in this submission specifically reflects the issues as they pertain to people with dementia. As there is a significant body of international literature on restraint and a series of draft policy documents (in an Irish context) circulating and available, the submission points the reader in the direction of these resources. The Alzheimer Society advocates strongly that the development of a restraint free environment policy should utilise the existing body of international literature, knowledge and best practice which is rooted in a strong and robust evidence base.

1.1 Restraint and the Person with Dementia

Restraint is the act of removing another person's freedom. The issue of restraint often arises in the context of dementia either because it is seen as a way of protecting the person with dementia or because of concerns about the safety of others. Rarely can the person give consent given the advanced cognitive decline that is the reality for majority of people with dementia living in long term care. Restraint in such circumstances, where consent cannot be given, may be experienced as highly demeaning and distressing. (Nuffield Council on Bioethics). Discussion on the use of restraints is difficult and can be extremely emotional. Often, there are varying opinions and clashes between the opinion of staff and family members.

1.2 Forms of Restraint

The most obvious form of restraint is *physical restraint* involving force or use of specific pieces of equipment.

Chemical restraint involves the use of pharmacological treatments including anti-psychotic drugs to calm or control the behaviour of the person with dementia by reducing level of activity or consciousness. There is a significant body of literature that indicates an over use of anti-psychotic drugs for people with dementia (All Party Parliamentary Group on Dementia, 2008). Recent research in the UK (Banerjee, S. (2009) concludes that the risks associated with using anti-psychotic medicine far outweigh the benefits for people with dementia.

Environmental restraint is limiting a resident to a particular environment (e.g. their bedroom) or excluding the person from an area to which they want to go (e.g. locking doors to prevent the person from going outside).

2. Principles of Restraint-free Environment Policy in Nursing Homes

The Alzheimer Society of Ireland identifies that a number of key principles should be reflected in any policy development on a restraint free environment.

The Alzheimer Society of Ireland recommends that a good restraint policy should be governed by the overall principles that restraint should always be *'the least restrictive option and undertaken for the shortest viable length of time'* (Commission for Social Care Inspection in the UK, 2007, p.51)

The core principles of respecting people rights, honouring their dignity and respect, and preserving their personhood through a person centre approach must be reflected.

The Alzheimer Society further endorses the principle that the use of restraint should only be as a genuine exception to the norm. (The Mental Welfare Commission for Scotland, 2006)

3. The Use of Restraint - what is the current practice?

What do we know about the use of restraint practices in long term care in Ireland? What are the most common forms of restraints being used? What is the policy and practice approaches in long term care? What training is delivered in relation to restraint? How does the person with dementia have their voice heard? In many ways we know very little about the policy and practices on the ground. There is a real need to understand the phenomenon in order to meaningfully respond and identify what is necessary to bring about the social, cultural, institutional and systematic changes needed to bring about a systemic wide shift in how to create a restraint free environment in long term care. There is considerable anecdotal evidence that the practice of restraint is widely used in nursing homes. Evidence from UK research by the Commission for Social Care Inspection (2007, pp.39-40) which explores the use of restraint in English care homes describes many examples of restraint that appeared to be routine rather than exceptional and “widespread suspicion” that restraint was often used not to ensure resident’s safety but in order to help staff manage their workloads.

The Alzheimer Society of Ireland recommends that a piece of research is commissioned to explore the issue of restraint in long term care in Ireland to answer the questions outlined.

4. The Solution to the Issue of Restraint: Implementing True Person Centred Dementia Care

The Alzheimer Society believes that people with dementia have a **right** to the best quality of care in the nursing home where they live. They are entitled to have their needs and wishes met with **dignity** and **respect**. In order to achieve this there must be a genuine commitment to **person centre care and planning**.

In fact, the Alzheimer Society argues that if there is a commitment to implementing person centred dementia care then the use of restraint will be absolutely minimised and in most cases obviates it altogether. Kitwood (1998) argued that person centred dementia care emerged as a response to a culture of care that reduced dementia to a strictly biomedical phenomenon which was task driven and relied on control techniques including chemical and physical restraints (Henson et al, 1998) that devalued the agency and individuality of the person with dementia. Kitwood believed that a focus on

dementia from the perspective of an organic mental disorder ignored the larger human issues and argued for a new paradigm in which the 'person comes first'. He sought to understand how the personhood was undermined for those living with dementia.

The Alzheimer Society of Ireland recommends that nursing homes in Ireland make a genuine commitment to the philosophy and practice of person centred care and person centred planning in the services they provide. This requires a visionary leadership and management, an entire shift in the culture of care in nursing homes, changes in the physical, social and environmental context within which the care is delivered, investment in human resources, recognition of carer worker contribution and the de-stigmatising of long term care for all of the stakeholders.

Dementia care mapping (DCM) is a method designed to evaluate quality of care from the perspective of the person with dementia. It is based on the philosophy of person centred care which promotes a holistic approach to care that upholds the personhood of the person with dementia. DCM is a powerful tool that enables the mapping and observations of the person with dementia over a period of time and recording information about their experience of care, analysing the data and feeding it back to staff which in turn is used in care planning.

The Alzheimer Society of Ireland recommends that Dementia Care Mapping is facilitating on a pilot basis in a number of nursing homes and if appropriate becomes a standardised tool in care planning and practice in long term care settings.

4.1 Alternatives to the Use of Restraint

A policy on a restraint free environment in nursing homes should highlight the alternative options to the use of restraint. This approach links in very closely with implementation of true person-centred care. A broad range of areas must be addressed in the alternatives options from examining the environment, activities and programmes, the approaches to care, the psychosocial programme and therapies and physiological strategies.

The Alzheimer Society of Ireland recommends the adoption of Australian model on the alternatives to restraint. (Australian Government Department of Health and Ageing 2004)

5. Decision Making on the Use of Restraint

It is important that responsibility for decision making in relation to restraint is removed from care staff and families. These decisions must be based on a sound clinical

assessment and judgement made by the appropriately qualified people and grounded in evidence and international best practice standards.

In relation to reaching a decision regarding the use of restraint, The Alzheimer Society of Ireland recommends the adoption of the Australian Department of Health and Ageing document 'Decision Making Tool: Responding to issues of restraint in aged care.' It is an internationally recognised best practice exemplar. It clearly outlines a comprehensive decision making tree to enabled decisions to be made in an objective, meaningful and respectful manner.

The Alzheimer Society of Ireland recommends a multi-disciplinary approach to making decisions regarding restraint.

5.1 Restraint or Enabler? The Intention Behind the Use of Equipment / Devices

Understanding the intention behind the use of particular pieces of equipment in terms of being an enabler or a restraint is central to any policy in this area. For example a lap tray enables the person to eat independently but if it left on for a number of hours it is effectively a restraint. Therefore it is the intent behind using the device that determines whether it is restraint or an enabler.

The Alzheimer Society of Ireland recommends that support and training for all management, support and care staff who are faced with decision making and implementation regarding the use of restraint. Ongoing and educational support and training for staff on restraint should be a feature of their training plans.

6. Developing the Policy Document – Recommended Resources

In 2009 the Health Service Executive (under the leadership of Ann Coyle National Planning Specialist) drew up two draft policy documents:

- 1. Draft Policy on the Use of Physical Restraints in Residential Care Units*
- 2. Draft Policy on the Use of Psychotropic Medication in Residential Care Units*

The Alzheimer Society, alongside a range of stakeholders, was actively engaged in the working groups and the drafting of the policy documents.

The Alzheimer Society of Ireland recommends to the Department of Health and Children that these documents are utilised as a core resource in the development of a policy on non-restraint in nursing homes.

The Alzheimer Society of Ireland recommends that the policy on restraint should adopt the NICE/SCIE guidelines on chemical restraint which make it clear that medication should be considered for 'behaviour that challenges' in the first instance only if there is severe distress or immediate risk of harm, with non-pharmacological approaches preferred in all other circumstances.

7. Restraint Reviews

Very often, restraint practices become the accepted norm and part of the mainstream in nursing home care. It is essential that there is a system in place that provides the opportunity for on-going review of the approach to and practices of restraint. Ideally, an external reviewer is appointed.

The Alzheimer Society of Ireland recommends that restraint reviews are a feature of a restraint policy and conducted by an external reviewer. The person with dementia should have an independent advocate appointed to support them in the review process.

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