Supporting People with Dementia in Sheltered Housing -  
The Experiences of a Dementia Services Advisor working for Housing 21
A report on the role and benefits of a Dementia Services Advisor. (Published with the permission of Experience South which is published by The National Housing Federation South Region).

Introduction

Housing 21 has appointed a Dementia Services Advisor. The need for such a post came from our Court Managers (Housing 21’s term for Wardens) who found increasing challenges in supporting a growing number of tenants with mild cognitive impairments and dementia living in sheltered housing. The Court Managers provide a low level support service to ensure the safety and well being of tenants. Their ability to provide this service was being challenged by the needs of these tenants.

This article explores the background to the new post, what it can offer, the challenges faced by me the post holder and the benefits the post can bring to the organisation.
Background and Context

The 2001 census revealed that for the first time the number of people over the age of 85 had exceeded one million. With an ageing population comes a number of challenges including the increasing number of people developing some form of dementia. By the age of 85 there is an incidence of 1 in 4 having some form of dementia, the most common (50%) being Alzheimer’s type. Dementia is an umbrella term used to describe a collection of symptoms in which the brain functions are gradually lost. This can be caused by a number of different illnesses or conditions. Apart from it causing memory loss, it can also affect the ability to use words and carry out previously familiar tasks.

The challenge for a Registered Social Landlord (RSL), like Housing 21, one of the largest providers of sheltered and Extra Care Housing (ECH) for older people, in England, is supporting tenants who either develop dementia during their tenancy or who come into Extra Care Housing as an alternative to residential care with a diagnosis of dementia.

Housing 21 aspires to ‘A Home for Life’, providing quality housing with care and support, espousing the philosophy of ‘ageing in place’. This reduces the number of times that a person has to move. Research has revealed that there is a close correlation between high mortality rates and moving people with dementia (Blanchetti, et al 1995, Anthony et al 1987, Winyard, g 1998). Housing 21’s aspiration for a ‘A Home for Life’ aims to enable older people to stay in their own home if they wish, for as long as practically possible.

Housing 21 has approximately 360 schemes or Courts, most managed by a Court Manager. Of these, 15 courts are defined as Extra Care Schemes, where care is provided on site and access to staff is available 24 hours a day.

Why create the Post?

Internal research in Housing 21 revealed that in sheltered housing 7% of residents have dementia.

Court Managers have identified the following issues:

- tenants experiencing acute or chronic confusional states
- demands from their tenants, carers and or family members for advice and support
- tenants complaining that life on the court was being disrupted by the challenging behaviours of other tenants e.g. ‘wandering’, door knocking, disorientation in time and place, self-neglect
- lack of support from the statutory health and social services

In addition, the challenges for Court Managers included,

- when and how to get services/support in for some tenants who lacked insight into their mental state
- how to encourage inclusiveness and a balanced community life
- striking a balance between maintaining independence, autonomy and dignity with their duty to oversee the welfare and safety of tenants.
The response of the tenants to tenants with dementia is mixed. Whilst some have been accepting others have not, viewing people with dementia as a threat to their ordinary way of life.

**What does the Dementia Services Advisor Offer?**

- professional advice and support to Court Managers concerning how to access services from the statutory agencies. This involves the tenant and or their carer wherever possible
- crisis support (for example preventing admission to hospital and/or residential care)
- policy and good practice guidelines on working with tenants and their carers in the early stages of dementia
- help for the Court Manager in knowing the difference between suspected dementia and treatable illnesses such as depression and offering information and advice on good practice in person centred dementia care
- support for court managers in knowing when to intervene with tenants at risk of harm either to themselves or other tenants and supporting them in taking action and sometimes unpopular decisions
- a telephone advice service in office hours
- work with tenants, when they want advice and support in how to support fellow tenants whom they know or suspect as having dementia
- advising Housing Managers on the appropriateness of sheltered or Extra Care Housing for people who may have advanced dementia

The post of DSA has a wide remit. The post holder is involved in devising a training programme, with Dementia Voice (the Dementia Development Centre for the south-west) on dementia awareness, advising on the design of new buildings, supporting home care staff, promoting assistive technologies for tenants with dementia. I also promote good practice based on the work that Housing 21 is undertaking in dementia care.

Housing 21 are supported by Dementia Voice, which has been a part of Housing 21’s group structure for the last 3 years and was also instrumental in the creation/development of the post and its ongoing development.

Whilst no other post exactly like this currently exists in other housing associations, some are making moves to provide a similar service. The Berry Retirement Village in Stoke-on-Trent, for example employs a ‘Well-Being’ Advisor. The role of the advisor is to detect health problems before they impact seriously on the life of the tenant, although this is not dementia specific. Methodist Homes for the Aged provide a Dementia Services Manager, whose role it is to ensure that the organisations nursing and residential provision maintains registration and quality standards in the provision of its dementia care services.
Challenges faced by the DSA

Numerous challenges and opportunities currently exist for a Dementia Services Advisor, including:

- promoting and awareness raising of dementia issues across a large geographical area and within a multi-faceted organisation
- challenging peoples perception of what is seen largely as diseased based model of illness and introducing a person centred model of care based on a social model of disability
- ‘fitting’ in a post that straddles both housing, property services, home care and new business development often working in isolation with no traditional team based support mechanism
- the need to evaluate the post with respect to its ability to sustain tenants with dementia in a model of sheltered housing that promotes autonomy and privacy
- advising Court Managers on practice issues and what can reasonably be expected from local authority services, which vary enormously from one area to another.
- raising awareness and challenging prejudices that exist amongst the tenants themselves, many of whom have a fear of developing dementia.
- promoting the implementation of assistive technologies. These ‘enabling’ technologies promote the ethics of good dementia care, perhaps in contrast to the ‘monitoring’ technologies such as Telecare, currently being promoted by government through its Preventative Technologies Grant that will become available to local authority social services departments in 2006.

What benefits and learning has it brought to Housing 21?

The following benefits for Housing 21 as an organisation are becoming apparent:

- an in house ‘expert’ that Court Managers and staff can refer to for advise and support. My previous post was as an Approved Social worker and Team Manager in an integrated health and social care team for older people and this experience has proved invaluable in carrying out my role.
- supporting Court Managers in knowing when to intervene and how to go about accessing services/support for tenants with dementia
- supporting tenants to maintain their tenancy when they may be under pressure by families, social and health care bodies to move into residential care
- opportunities for business promotion e.g. establishing a specialist home care service for people with dementia.
- making the association’s aspiration ‘a home for life’ more of a reality

Primarily the role creates the opportunity to enhance the quality of life and well being for many older people in sheltered housing.

Case Study prepared by David Self for the Housing Learning & Improvement Network
Case study no.1: Extra Care Strategic Developments in North Yorkshire  
(01.09.03)

Case study no.2: Extra Care Strategic Developments in East Sussex  
(01.09.03)

Case study no.3: ‘Least-use’ Assistive Technology in Dementia Extra Care  
(02.02.04)

Case study no.4: Tenancy Issues - Surviving Partners in Extra Care Housing  
(01.06.04)

Case study no.5: Village People: A Mixed Tenure Retirement Community  
(15.10.04)

Case study no.6: How to get an Extra Care Programme in Practice  
(15.10.04)

Case study no.7: Sonali Gardens - An Extra Care Scheme for Bangladeshi and  
Asian Elders  
(11.01.05)

Case study no.8: The Kent Health & Affordable Warmth Strategy  
(26.04.05)

The Housing LIN welcomes contributions on a range of issues pertinent to Extra Care  
housing. If there is a subject that you feel should be addressed, please contact us.