

## DESIGN AND GOOD PRACTICE GUIDE DEMENTIA CARE AND SUPPORT IN EXTRA CARE HOUSING



*Extra care housing provides safe and secure self-contained accommodation for vulnerable adults who require varying levels of care and support to enable them to live independently in a home environment*

<b>CONTENTS</b>		<b>Page</b>
<b>BACKGROUND</b>		<b>3</b>
<b>INTRODUCTION</b>		<b>6</b>
<b>SECTION 1</b>	What is dementia?	<b>7</b>
<b>SECTION 2</b>	General principles for dementia care in extra care housing	<b>10</b>
<b>SECTION 3</b>	Exterior design of extra care housing for people living with dementia	<b>12</b>
<b>SECTION 4</b>	Interior design of extra care housing for people living with dementia	<b>13</b>
<b>SECTION 5</b>	Individual's accommodation	<b>22</b>
<b>SECTION 6</b>	Lighting design for people living with dementia	<b>25</b>
<b>SECTION 7</b>	Meaningful occupation and activity	<b>28</b>
<b>SECTION 8</b>	Care and support delivery	<b>36</b>
<b>SECTION 9</b>	Staffing	<b>45</b>
<b>SECTION 10</b>	Medication	<b>47</b>
<b>SECTION 11</b>	Safety and security	<b>49</b>
<b>SECTION 12</b>	Assistive Technology	<b>50</b>
<b>SECTION 13</b>	End of life care	<b>52</b>
<b>ACKNOWLEDGEMENTS</b>		<b>54</b>

## BACKGROUND

North Yorkshire Council is engaged in an ambitious project to facilitate the delivery of accommodation with care to meet the needs of our current and future communities.

This includes working with partner organisations to enable the provision of extra care housing schemes; core and cluster accommodation; specialist housing and supported accommodation to meet the needs of vulnerable people in the county, including: -

- older people
- people with a learning disability
- people with mental wellness requirements
- long-term conditions including physical disability
- complex needs
- cognitive impairment
- sensory impairment

This Guide focuses on people living in extra care housing who are living with dementia.

### Extra Care Housing

The overall purpose of any extra care housing (ECH) scheme is to provide safe and secure self-contained accommodation for vulnerable adults who require varying levels of care and support to enable them to live independently in a home environment.

The aim is to ensure that vulnerable adults in North Yorkshire benefit from services in their own home and, where appropriate, are able to access alternative accommodation to meet their care and support needs, whether as a tenant or leaseholder. Based on the Council's experience of supporting people living with dementia, this guidance is likely to reinforce achieving best outcomes.

The care and support service provider will ensure there is staff available to provide residents with appropriate practical, emotional, personal and social care in their own home. In addition, they will promote independence and health and wellbeing in accordance with any on-going assessment of needs and through the on-going improvement, maintenance or minimised deterioration of: -

- normal daily living functions
- ability to self-care
- mobility
- confidence and independence in own home
- physical and mental health

An Operational Protocol between all partner organisations will be in place to quality assure the care and support services in extra care housing schemes. It is expected that the care and support services provide support that: -

- contributes to the initial reduction of the levels of care and/or support previously received by the resident <sup>1</sup>before entering the scheme
- supports the on-going care and support needs of residents and reduces the likelihood of admission to long-term care
- contributes to the prevention of hospital admission, re-admission and enables early discharge
- contributes to supporting people to live independently, stay healthier and recover quicker from illness or accident
- enables people to be supported to remain in their own home and supported to die in their own home if that is their wish
- enables people living with dementia to live independent and active lives without the need to move to more restrictive accommodation

### **Ethos of The Extra Care Housing Scheme**

Residents who have been assessed by Health and Adult Services (HAS) local commissioners using the Fair Access to Care Services (FACS) criteria may live as assured tenants or leaseholders with security of tenure in their own self-contained apartments within an extra care housing scheme.

North Yorkshire Council's strategy aims to reshape the countywide provision of care accommodation options and services in order to offer residents increased choice and independence.

### **Extra Care Housing Principles: -**

- promote independence, prevention and wellbeing
- improve outcomes for residents and their carers
- enable two-way community interaction to provide activities, lifelong learning and social interaction
- give people choice and control over their care and support needs via the personalisation agenda
- give people control over their personal finance arrangements including having access to welfare benefits with a view to maximising their income
- provide housing, care and support solutions to all vulnerable adults of all ages and across all needs

---

<sup>1</sup> We are using the term 'resident in its true sense, as a resident of a housing model rather than a residential institution

- be mixed tenure and tenure blind
- involve and consult with people of all ages and need, who are likely to live in or use the facilities and services provided at the scheme
- include a specialism where there is an identified need such as a memory clinic or specialist day service
- offer choice and control with a wide range of innovative, high-quality and flexible care options that are joined up and seamless

With good quality design and flexible care and support services, the aim of extra care housing will be to enable a person living with dementia to live in their ECH property for life, where it is practicable, safe and it is their wish to do so and not to move someone into residential or nursing homes because their support becomes difficult or expensive. The ethos is about finding a solution to support that person appropriately, safely and in line with their wishes.

The preventative role of extra care housing should be recognised including its increasing use as a site for the delivery of community health services to people with complex needs, both to residents within extra care and the local community. The benefits of extra care housing are recognised by relatives of people living with dementia. In some cases, family relationships are said to improve when people living with dementia move to extra care housing. Residents and relatives are reassured that there is someone on site to keep an eye on things. Nearly all of the residents living with dementia are frequently visited by family members who previously provided informal support.

ECH also provides potential benefits and improvements for carers looking after relatives living with dementia (e.g., partners and family). The nature of the environment, the specialist design features incorporated into the scheme and the fact that care and support is on site, reassures the carers and families that their relative will be cared for appropriately. An example of this is that couples can carry on living together and, where one of them is living with dementia, the other can continue to support their partner with the knowledge that should they need some help or a break from their caring role, it will be available.

*Good design has a key role to play in terms of improving the quality of life for everyone who lives and works in extra care housing. It is particularly important that people with dementia have a stimulating environment and good opportunities for social interaction. Therefore, the ability to move around the building independently is particularly important to people with dementia*

*Opening doors to independence – summary: A longitudinal study exploring the contribution of extra care housing to the care and support of older people with dementia, Sarah Vallely, Simon Evans, Tina Fear & Robin Means.*



## INTRODUCTION

This guide is not designed to be considered in isolation and should be read alongside North Yorkshire Council's Design and Ethos Guide for extra care housing and the Bring Me Sunshine Dementia Strategy which can be downloaded at:

[68982 Dementia Strategy proof v2 04Oct.pdf](#)

[Bring me sunshine: the North Yorkshire dementia strategy | North Yorkshire Council](#)

The Guide is a combination of best practice research from a wide variety of sources. The content of the guide predominantly suggests valuable design features that are beneficial to people living with dementia, however, some aspects of the best practice references are essential, particularly where they are linked to policies and procedures.

Many extra care schemes erroneously promote themselves as designed specifically for people living with dementia or as being dementia friendly. Often this claim can be as a result of one dementia specific design feature being incorporated such as coloured corridors to aid orientation being introduced into a building designed to meet the needs of older people without cognitive impairments. A specially designed dementia scheme is different, in that it is designed for people living with dementia first and based on the philosophy that good dementia design is good design for all older people.

An example of this is the dementia design principle of 'form following function'. We know that people living with dementia require a number of external cues in order to process usage of the environments in which they find themselves; a restaurant must look and feel like a restaurant for someone living with dementia to recognise it as such. The creation of an internal street which has shops, restaurants, hair salons or a pub coming directly off it provides the external cues necessary for residents to recognise very clearly its function and orientate themselves around the space. If it's possible to mirror the local architecture of the town or village in which the scheme is built and employ the same street design and shop fronts, that will further increase the familiar external cues available.

This attention to evidence-based dementia detail should run through every design and environmental feature within the building. Individual apartments should be designed so that they can be fitted with the very latest in terms of assistive technology such as lighting that is activated by a person's movement and that can direct them to the toilet at night; voice prompts that can orientate them in terms of day and time and bed sensors that can allow sleep monitoring. Kitchens should have glass-fronted cupboards so individuals can see the food contained within, as evidence shows that this design adaption leads to increased food consumption and a decrease in malnutrition rates in people living with dementia.

Barriers and obstacles like locked doors can be distressing for people living with dementia and can lead to 'challenging' behaviours. An innovative solution is the use of sensor locks on apartment doors which react to a proximity fob worn by the resident.

The sensor for the fob can be set at varying distances and opens, closes and locks the apartment door automatically so that the apartment is secure whether or not the resident is at home, but the resident doesn't need to be concerned about carrying – and possibly losing - keys. The use of these locks can negate the need to use progressive privacy doors to areas where specialist apartments for people living with dementia are located, while still providing security to the apartment.

The environment is only one aspect in the delivery of specialist dementia care; a well-designed environment must be complemented by an excellent evidence-based dementia care and support system. The care and support delivered within a scheme needs to provide 'real' person-centred care that utilises the environment in order to maximise the relationship between the carer and the person living with dementia. The scheme should support the development of new approaches in the delivery of dementia care and support. The Health and Social care dementia services, hospital in-reach services and specialist end of life care are a few of the services that could be developed from schemes and for which models exist within other European countries.

## SECTION 1: WHAT IS DEMENTIA?

Dementia is a term for a range of progressive and terminal organic brain diseases.

Types of dementia include: -

- Alzheimer's disease accounts for 62 per cent of dementias in England. It changes the chemistry and structure of the brain causing brain cells to die
- Vascular dementia is caused by problems with the supply of oxygen to the brain following a stroke or small blood vessel disease. Vascular dementia along with those mixed vascular with Alzheimer's dementias make up around 30 per cent of the total. Conditions that affect the circulation of blood to the brain, such as hypertension, can contribute to vascular dementia
- Dementia with Lewy Bodies is caused by protein deposits that develop inside nerve cells in the brain and interrupt its normal functioning. It shares symptoms with Parkinson's disease, including slowness of movement. It accounts for 4 per cent of dementias in England
- Frontotemporal dementia is a rare form of dementia, encompassing Pick's disease, and affecting 2 per cent of people living with dementia in England. It often affects the under 65s, with dramatic effects on behaviour and personality, rather than memory, in the early stages
- Korsakoff's Syndrome is a brain disorder usually associated with heavy alcohol consumption over a long period. Although Korsakoff's Syndrome is not strictly speaking a dementia, people with the condition experience loss of short-term memory

Disease progression varies considerably, but broadly falls into three phases: -

### Early dementia

This phase is often only apparent in hindsight. At the time it may be missed, or put down to old age, being stressed or overworked. The onset of dementia is very gradual, and it is often impossible to identify the exact time it began. During the early phase of dementia, the person may: -

- appear more apathetic, with less sparkle
- lose interest in hobbies or activities
- be unwilling to try new things
- be unable to adapt to change
- show poor judgement and make poor decisions
- be slower to grasp complex ideas and take longer with routine jobs
- blame others for 'stealing' lost items



- become more self-centred and less concerned with others and their feelings
- become more forgetful of details of recent events
- be more likely to repeat themselves or lose the thread of their conversation
- be more irritable or upset if they fail at something
- have difficulty handling money

### Moderate dementia

During the 'moderate' phase, the person's problems are more apparent and disabling. They may: -

- be very forgetful of recent events. Memory for the distant past seems better, but some details may be forgotten or confused
- be confused regarding time and place
- become lost if away from familiar surroundings
- forget names of family or friends, or confuse one family member with another
- forget saucepans and kettles on the stove. May leave gas unlit
- wander around streets, perhaps at night, sometimes becoming lost
- behave inappropriately - for example, going outdoors in their nightwear
- see or hear things that are not there
- become very repetitive
- be neglectful of hygiene or eating
- become angry, upset or distressed through frustration

### Severe dementia

During the later stages of dementia, the person can be severely disabled and may require total care. At this stage, the person may: -

- be unable to remember - for even a few minutes - that they have had, for example, a meal
- lose their ability to understand or use speech
- be incontinent
- show no recognition of friends and family
- need help with eating, washing, bathing, using the toilet or dressing
- fail to recognise everyday objects
- be disturbed at night
- be restless, perhaps looking for a long-dead relative
- be aggressive, especially when feeling threatened or closed in
- have difficulty walking, eventually perhaps becoming confined to a wheelchair
- have uncontrolled movements

Source: *Better Health Channel, dementia through all its stages*

## SECTION 2: GENERAL PRINCIPLES FOR DEMENTIA CARE IN EXTRA CARE HOUSING

Fundamental dementia design guidance includes the following recommendations: -

- observing a domestic scale
- creating a homely environment for residents
- using familiar materials, textures and colours

It can be common for people living with dementia to also suffer serious sight loss or impairment and it is important that the interior design of extra care schemes is sensitive to the very particular problems faced by people with both conditions. The loss or serious impairment of sight can be devastating for people and, coupled with a diagnosis of dementia can have a hugely negative impact on people's emotional wellbeing.

Assisting people as much as possible by using sympathetic and effective design can go a long way to enabling people to adjust better to their symptoms and thereby reduce the possibility or extent of depression.

Some people living with dementia may experience hallucinations, even those with sight loss or impairment. For this reason, it is important that consideration is given to patterns and pictures so that misleading messages do not trigger a hallucination. For example, pictures of skeletal trees or faces and some animals can be misinterpreted by a person living with dementia and should therefore be avoided. Great thought should be given to the selection of pictures and statuary to ensure they do not result in any confusing or frightening messages.

There may be a reduced capacity for some people who are living with dementia to be able to judge risk or foresee danger; forgetfulness is another issue which could lead to danger in some areas. It is common for people living with dementia to get lost trying to find their way around a building. This reflects a person forgetting such basic information as the location of one room in relation to another. If numerous visual cues or reminders are incorporated into the design, these can help by acting as way-finders and make the situation less stressful and confusing for those residents and hopefully reduce the evidence of challenging behaviours that could lead to other residents being unsettled.

One unique approach, referred to as the 'household' model which was created by Steve Shields at a facility in Kansas called Meadowlark Hills, focusses on supporting people living with dementia in a domestic rather than an institutional setting. A 'household' is usually made up of a cluster of apartments set around 'domestic' communal areas such as a kitchen, lounge and dining area. The décor is domestic in nature, with lots of familiar things around associated with normal life like books, pictures, knick-knacks and general household items that people living with dementia will recognise and want to pick up, touch, look at and use as they would if they were in their own home. The staff dress casually and do not wear uniforms or badges, the residents are encouraged and supported to help out with the day to day running of the 'household'. The emphasis is

on the people living with dementia being occupied but not necessarily with planned time-specific organised activities as people living with dementia often have limited capacity to maintain attention for long periods of time.

The Meadowlark Hills methodology advocates that “there is comfort, security, freedom to make choices, the normal smells and sounds you’d find in your own home – down to chatting over tea around a kitchen table.”

### **SECTION 3: EXTERIOR DESIGN OF EXTRA CARE HOUSING FOR PEOPLE LIVING WITH DEMENTIA**

The exterior design of extra care housing schemes should provide a safe, enclosed and secure environment for residents.

The transition from interior to exterior space should progress gradually to ensure there is not a sudden change of environment or temperature. The access to outdoor space such as a garden, terrace, patio or balcony should be easily accessible from the building and there should not be steep slopes or other barriers within the outdoor area. A level, non-slip hard surface should be incorporated (that allows for a shuffling gait) with wander paths that are wheelchair accessible, and which return people to their starting point.

The lighting to the main access routes through the garden and at the main entrance must be sufficient, and the external lighting should be evenly distributed and avoid pools of bright light and deep shadow contrasts.

Areas created in the garden ought to provide a sense of moving from one space to another for example a trellised gate, with resting areas provided throughout the garden, some of which should be protected from direct sunlight and wind. Familiar garden objects such as tools, washing lines, wooden seats, bird tables and greenhouses should be in easy view and accessible to residents.

The garden should be well-maintained and attractive, with a range of year-round planting offering a range of stimulation to the senses. The careful placement of planting can be used to help guide residents away from exit areas which they should be discouraged from using.

Research suggests that developing areas with a greenhouse, a potting shed, planting areas or even aviaries create a familiar environment for residents and can be utilised to encourage outdoor activities, both with and without support from staff.

The use of adult outdoor gyms has been recognised to be of benefit to older people, even those with reduced mobility. The equipment has been designed to improve joint mobility, muscle strength and to increase the overall activity levels of older people as well as being fun to use.

Exterior fencing should be designed in a way which still allows residents views of the outside world.

Being creative with the outdoor space is important to providing residents with a stimulating and attractive space in which to wander safely or to participate in therapeutic and meaningful activities.

## SECTION 4: INTERIOR DESIGN OF EXTRA CARE HOUSING FOR PEOPLE LIVING WITH DEMENTIA

At the time of publication, 28 per cent of residents living in extra care housing in North Yorkshire are living with dementia. Extra care housing is providing care and support to those people, many of whom are very old and have additional complex health needs. Many older people living with dementia recognise that, of the housing options available to them, extra care is more suitable to helping them maintain their independence:

*“It’s got everything really...it can never equal living in a family, but it is the next best thing”.*

*(EC Resident living with dementia)*

*“in Extra Care Housing, not only is Mum able to retain the status of a tenant in modern spacious accommodation but she receives high quality care from enthusiastic carers who are specifically trained to respond to her particular needs and demonstrate genuine interest in her wellbeing. Directly and indirectly these same carers provide my brother, sister and me with peace of mind as well as the help and support that enables us to enjoy spending time with Mum. We are now able to undertake our responsibilities to the rest of our families and to our work in the reassuring knowledge that Mum is safe in a kind and caring environment”.*

*(Family member of resident living with dementia)*

As far as design is concerned, it is helpful to see dementia as a disability. This approach provides clear pointers to the disabilities for which a building needs to compensate.

Dementia as a disability is characterised by: -

- impaired memory
- impaired reasoning
- impaired ability to learn
- high level of stress
- acute sensitivity to the social and built environment

There is a national consensus on building design for people living with dementia. This can be separated into two areas: one being the principles of design, the other an agreement on design features.

The consensus on the principles of design: -

- compensation for a disability
- maximisation of independence



- enhancement of self-esteem and confidence
- demonstrate care for staff
- be orientating and understandable
- reinforce personal identity
- welcome relatives and the local community
- allows control of stimuli
- responds to people's need to be safe to move around their environment safely

The consensus on design features includes: -

- small size
- familiar, domestic, homely style with plenty of scope for ordinary activities (domestic-style kitchens, washing lines, garden sheds)
- unobtrusive concern for safety
- different rooms for different functions
- considering age-appropriate furniture and fittings
- safe outside space
- personal space big enough for lots of personal belongings
- good signage and multiple cues where possible (e.g., signs, smell and sound)
- use of objects and colour orientation
- enhancement of visual access
- controlled stimuli especially noise
- minimise barriers for accessing spaces and facilities

Incorporating the use of open plan layouts should increase visibility for the residents for example visibility from reception area to entrance, waiting area, toilets and access points to other parts of the building. Providing well-lit, inviting entrances to rooms, natural lighting, changes in floor and wall textures, colours, identifiable architectural features, recognisable and distinctive individual room designs help to compensate for residents' sensory and memory losses. It must also be considered that a number of people living with dementia may have other sensory disabilities; therefore, hearing and sight loss may be prevalent along with the cognitive impairment. The scheme should also have good access throughout for those with physical or mobility problems including wheelchair users.

Ideally doors should open against the wall, into the various rooms, providing good clues to a particular room's function, by giving an immediate view of the room and its

contents. The length of corridors is best minimised in areas that are used frequently by residents.

Clear glazed screens to communal areas should permit residents to understand the use of a room without resorting to signage. Staff must ensure that lights are on first thing each day to encourage people to enter rooms and use the spaces available to them. Seating in communal areas should be provided at frequent intervals providing people with the opportunity to rest, if they need or wish to do so. Residents may wish to sit outside of their own apartments but not necessarily in busy communal areas, so seating in quieter locations but with a view of what is going on should also be provided.

The design must incorporate fully accessible toilets which should be located close to reception and waiting areas, ideally with contrasting colour schemes for example, the toilet seat contrasting with the toilet and the wall it is fixed to. Doors should be offset from public

view to enhance privacy and dignity. If passive infrared sensors (PIR) are used for lighting, they should be set for an extended period of time so that people are not distressed by being suddenly plunged into darkness.

Access to the reception area should be easily visible from and in close proximity to the entrance point. Design of the communal areas ought to consider the integration of display spaces for personal belongings to help stimulate residents' memories and identity. The use of imaginative and unobtrusive designs for example, to make cupboard or staff-only doors an integral part of the overall environment is desirable and can help to guide people away from areas that they shouldn't access.

Window designs should have low sill levels to allow people to view outside from a sitting position, including people sitting in a wheelchair. The windows should provide easily controllable ventilation for example trickle vents and hung to avoid direct drafts at sitting level. If the building has more than one accessible storey, a minimum of two lifts must be incorporated into the design or a stair lift, or ramp access provided to the storeys not on ground levels.

The lifts should not have finishes that are highly reflective or use mirrors. The lift should incorporate speech control for notifying floor levels and have passenger controls in braille. Through-and-through lifts should be avoided as this leads to confusion.

## **4.1 DÉCOR**

Colour change as a means of wayfinding is an established method within extra care housing but should be used only as a basic method; some people may be colour-blind or not respond to colour as a trigger for mapping their way around the scheme so, for instance, using the same picture outside the lift on each floor but changing the colour may not be sufficient. Instead, definite articles should be used, such as placing a large pot Dalmatian dog outside, the assisted bathing room; having an artificial red rose plant

on the way to the dining room; placing a console table with lamp outside the lounge etc. People are more likely to recognise furniture and articles than colours and pictures.

In communal areas it is beneficial to consider the use of contrasting colours to aid visibility. For example, skirting boards in colours that contrast with the wall and floor finishes can help people to distinguish between the different surfaces.

Digital picture frames are a good idea, in that they can display pictures that can change with the seasons or other relevant themes and can be useful prompts for residents. If signage is required, it should be fixed to the doors they refer to, rather than adjacent wall surfaces, as this can cause confusion and disorientation for people living with dementia. Signage should also be placed at an appropriate height, be easily visible and easy to read. As older people, including those living with dementia, often have other cognitive impairments, it would be beneficial to utilise signage that includes braille.

## **4.2 FIXTURES, FITTINGS, PICTURES AND LOOSE FURNITURE**

Additional communal facilities such as libraries, hairdressing salon and treatment rooms should be equipped with readily visible and recognisable furniture and fittings that clearly express their uses. The furnishings and decoration should be comfortable and suggest a non-institutional environment.

Representations of real-life objects and complex designs should be avoided in wall, floor and curtain finishes as complex patterns can cause confusion and hallucinations for people living with dementia and they can also be difficult to interpret for people with vision impairments.

The design of furniture and the layout of the rooms must enable people, rather than restrict them. Chairs, tables and sofas etc must be of an appropriate style to allow people to get in and out easily. Providing a variation to furnishing styles for example a selection of chair designs, heights, with or without armrests, gives residents more choice. Mirrors in communal areas are not considered to be appropriate but if they are provided, they must be easily covered.

Handrails throughout the communal areas should be easy to use and comfortable and painted in a contrasting colour to the walls, with clear safety features to indicate where they end.

The use of technology such as Wanderguard door sensors and closers should be maximised to support residents in their independence and usual personal activities.

## **4.3 WAY-FINDING**

Some people living with dementia feel compelled to walk about or leave their homes. This can be worrying for those around them and can at times put the person at risk; therefore, it is important to find a solution that enables the person to continue their normal daily behaviour, preserves their independence and dignity but keeps them safe.

It can be very troubling when a person living with dementia starts to walk about in what may appear to be an aimless way. They might get up and leave the house in the middle of the night, or they might knock on a neighbour's door at inconvenient times of the day. People living with dementia can often experience problems with orientation, which may cause difficulties in finding their way home. This can make their loved ones feel very anxious and concerned for their safety. It can be reassuring to know that this type of behaviour does not last - it seems to be a phase of the condition that some people go through. In addition, most people living with dementia usually retain their road sense.

There are many types of assistive technology that can help to support a person living with dementia and staff caring for them to manage wandering, for example a Property Exit

Sensor (PES). These sensors can be helpful if a person is disorientated or confused when they leave their home, or if they sometimes go out at inappropriate times during the day or night. The sensors are placed above a front door and/or a back door and they detect when someone leaves the property and does not return within a pre-set period of time. When this happens, the staff are automatically alerted to assist them. A property exit sensor can be set to work at certain times, during night-time hours for example. The sensor can also trigger an alarm if the person accidentally leaves their door open.

There is also a system called Wanderguard that can be fitted to the main entrances of ECH schemes. With their approval, the person living with dementia wears a bracelet which will activate a call to the staff when they leave the building. The purpose of the system is to alert the staff who can then try to establish the reasons for that person leaving the building, it might be that they simply want to go for a walk outside; the staff member can then accompany them to ensure their safety. This type of technology can often help to reduce challenging behaviour if the staff member is able to support the person with their intended task rather than just taking them back in the building because it is easier to do so which often leads to frustration for the resident.

Why might people living with dementia walk about?

The first thing to consider is why the person might be doing this. Once you identify what the person is trying to achieve, you can start to find ways to meet their needs, thus reducing frustration and helping to retain independence. There could be a number of reasons for their walking: -

- continuing a habit
- relieving boredom
- using up energy
- relieving pain and discomfort
- responding to anxiety
- feeling lost
- memory loss

- searching for the past
- seeking fulfilment
- getting confused about time

*Leading the fight against dementia: Moving and Walking about, Alzheimer's Society*

Using landmark objects such as memorabilia and artwork can enable residents living with dementia to find their way about, by associating objects with places. Good practice would be to encourage residents to personalise their own spaces, for example providing a shelf next to each front door to display a photo, picture or item which enables them to recognise their home.

Corridors should be designed so that they lead to meaningful destinations, not 'dead ends' and there should be clear and uncomplicated circulation routes incorporated into designs that are easy to interpret and reduce the possibility of residents getting lost and frustrated. Ideally corridors should have a curved turn rather than change of direction with a right angle. This leads people along the corridor and gently around the corner rather than them looking along the corridor and the corridor appearing to abruptly end. Decorative features can be used to encourage people to move around appropriately and safely i.e., footprints in the carpet, hands painted on walls with fingers pointing in the right direction etc.

#### **4.4 DINING ROOM**

Ideally the dining room should be small and domestic in scale and the room should be easily accessible from other areas of the building. The arrangement of the seating can assist in creating a positive and managed dining experience by breaking the room up into smaller dining areas. This can be achieved through placing planters or other forms of room dividers. Residents should be encouraged to participate in preparing the dining room for meals for example setting tables, folding napkins or filling condiments. Dining furniture should be of an appropriate style and suitable for wheelchair users, the use of sliders on chairs can make getting in and out of seating areas easier. Staff should be encouraged to eat alongside residents and residents should be encouraged to invite relatives and friends to dine with them. The whole experience of dining should be calm, friendly and enjoyable.

Crockery and cutlery are more user friendly if they are a contrasting colour to the food being served, for example, with a strong border or a plain bold colour. This should enable the person to see what is on their plate or in their cup and should therefore encourage food consumption. The use of familiar tableware can provide people living with dementia clear signals about meals and help them to maintain their capacity to eat independently for longer.

Other useful tips to encourage a person to eat well: -



- to serve one course at a time and remove unnecessary distracting objects from the table
- allow plenty of time for the person to eat - do not try to rush them
- try to keep noise or activity in the environment to a minimum
- make sure there is adequate lighting in the dining area
- serve food that is familiar to the person (get to know what they like)
- encourage staff and family members to sit and eat with the person living with dementia so that they can follow their lead

Some other approaches to consider for making mealtimes less stressful include: -

- keep eating simple – not all food has to be eaten with cutlery if this is becoming difficult, finger foods can be a nutritious and easy alternative
- keep in mind a person's past history with food – they may have always had a small appetite, been a voracious eater or had a craving for sweets
- watch food temperatures – while warm food is more appetising, some people with dementia have lost the ability to judge when food or drink is too hot
- offer support – spoiled food in the refrigerator, hiding food or not eating regularly may all be signs that someone living alone needs more support
- offer plenty of fluids – regular drinks of water, juice or other fluids are essential to avoid dehydration. Many people living with dementia do not get enough fluids because they may forget to drink or may no longer recognise the sensation of thirst
- be prepared for changes – many eating problems are temporary and will change as the person's abilities deteriorate

Ideally, toilet facilities should be fully accessible from the dining area and preferably visible from a seated position or well-signposted, so that when a resident wants to use the bathroom, they know in which direction to head.

## **4.5 SENSORY ROOM**

Sensory loss is often a symptom of dementia, particularly sight and hearing loss. The quality of life for people living with dementia and sensory loss can be significantly improved if symptoms are recognised and addressed early on and benefit from a formal diagnosis.

Best practice principles suggest that people living with dementia are best suited to domestic living environments and that good design can play a significant part in helping people to overcome sensory and cognitive problems such as memory loss, limited sight and other cognitive impairments.

North Yorkshire Council supports the addition of sensory rooms within extra care housing schemes that use lighting, smells and sound to help stimulate senses for residents living with dementia. Sensory rooms do not have to contain expensive or high-tech equipment, in fact the more the home environment can be duplicated, the better.

Ideally the room should be centrally located to allow easy access and so that it can be easily monitored by staff. It is acceptable to have windows in the room as long as heavy curtains are available to block out the light when needed. It is important that ways are sought to maximise the use of the room so that it becomes a valuable asset to the scheme.

The design of sensory rooms should focus on a calming and soothing environment promoting relaxation. They should be carpeted and have comfortable homely furnishings and calming colours for example pale blues or greens. Lights, ideally, should be on a dimmer switch.

Staff supporting people living with dementia will be provided with training, so everyone is comfortable and knowledgeable regarding sensory approaches to treatment.

The room might include some of the following suggested equipment: -

- electrified motion and sound wall pictures, bubble lamps
- fibre optic sprays or lava lamps
- plants
- relaxation and nature sound CDs
- a variety of music for individual tastes
- relaxation tapes
- books on tape (short stories, comedy, poetry etc)
- aromatic supplies and aroma diffuser
- mobiles
- vibrating pillow or back or foot massagers
- a selection of washable blankets
- self-grooming items such as hairbrushes, nail care kits
- photographic books
- therapy balls or beanbags
- fish tank

It is important that managers of the scheme develop protocols to ensure that the use and safety within the room is adhered to and might allow for the following issues: -

- maximum number of people who can use the room at any one time
- safety and precautions (allergies, cardiac and respiratory precautions, seizure history, sensory sensitivities, trauma history, behavioural issues)
- guidelines for staff: who is allowed to run groups or provide individual treatment?
- staff training requirements
- rules and safety
- scheduling use of the room
- level of supervision required
- conduct expectations when using the room
- responsibility for locking and safety of the room
- facility regulations (wash ability, fire resistance, and electrical standards)

There is well-researched work going on in extra care schemes around reminiscence projects and music therapy but cognitive rehabilitation techniques such as memory training and cognitive stimulation therapy focus on improving outcomes for people. There is also some research about the use of dolls, and it may be useful to have these available if it is appropriate for an individual to care for a doll. (See Section 7.1 Doll therapy for People Living with Dementia).

## SECTION 5: INDIVIDUALS' ACCOMMODATION

When an extra care scheme includes units of accommodation specifically designed for people living with dementia, they should be designed with the aim of enabling people to move in and settle even when they are well-advanced in their condition. There are a number of examples of different designs being developed across the county and this will include an element of registered accommodation. More details are available about design models from the Extra Care Team.

Although general extra care apartments are designed to be suitable for all people including people living with dementia and their partners, current best practice recommends one bed/2 person apartments that provide, as a minimum, the same rooms, fixtures and fittings as a general extra care apartment. The main difference being that an apartment for a person living with dementia can be open plan (except the bathroom for privacy and dignity reasons) enabling the resident to see their entire apartment at a glance. There should be landmarks to assist people with finding their way to certain areas (e.g., their bedroom) such as furniture, plants, wall hangings, artwork and generally items that are recognisable, attractive and interesting to that person.

### 5.1 KITCHEN DESIGN

The kitchen should be fully equipped as some people living with dementia enjoy cooking or helping to prepare meals. Ideally the kitchen should include: -

- at least two glass-fronted units; one base and one wall, with internal lighting
- a fridge/freezer or a glass-fronted fridge
- one open-shelved wall unit
- under-pelmet lighting
- obvious contrast between worktop/tiles/units/floor
- a safety cut-off for oven and hob
- all appliances to be white (rather than stainless steel for instance) as white is more easily recognised as kitchen equipment and the units should not be integrated into cupboards
- fuse switches will be hidden inside a cupboard so that the resident can't switch off the fridge etc
- there will be a small lockable cupboard included for the safe storage of personal medication

Residents should be encouraged to take part in normal kitchen activities such as meal preparation, cooking, making drinks and tidying up – activities that they would have undertaken prior to moving into an extra care housing scheme. The use of technology such as heat sensors, flood monitors and gas cut-off valves may be necessary to

ensure the safety of the residents, with some of the activities requiring the support of a care worker.

Adequate time should be incorporated into a person's support plan to allow them to participate in such activities.

## **5.2 BATHROOM DESIGN**

The bathroom should have a mirror fitted over the basin; however, this should be easily covered or removed in case a resident finds the provision of a mirror distressing. Ideally, the toilet should be situated so that it can be seen from the bed, thereby enhancing dignity and assisting with the resident's continence. Grab rails in the bathroom should contrast in colour, chrome being the preferred option. Controls for showers should be uncomplicated and easy to use and the flooring of shower cubicles should blend in and be flush with the rest of the floor. Other fixtures such as toilet roll, or toothbrush holders should also contrast in colour to the wall tiles.

There will be a free-standing shower chair rather than a wall-mounted drop-down stool as a free-standing chair gives more flexibility.

The resident should be able to easily see and access their toiletries, therefore, a shelf or open unit in the bathroom would be beneficial and the basin should be of the type that includes a generous amount of put-down space.

An easily accessible emergency pull cord must be provided in the bathroom.

## **5.3 BEDROOM DESIGN**

The bedroom should have access to private and fully accessible en-suite facilities. The room should have good levels of natural and general lighting with supplementary local lighting.

Natural lighting should be controllable to minimise glare and shadow contrasts. Touch control lighting could also be considered.

The resident's bedroom (or bedroom area in an open plan apartment) should be personalised, protected, easily visible, identifiable and secure. The function of the bedroom area should be made recognisable by a wide range of sight lines to the bed from both inside and outside the room. The layout of the furniture is important to allow for ease of movement and wheelchair accessibility. The head of the bed is best positioned to allow the occupant to identify the location of the toilet. The floor threshold between spaces that the resident is to move between should be consistent in colour e.g., bedroom entrance to en-suite, so as not to cause 'visual barriers' for the resident. Windows in the apartments should ideally have restrictors to limit opening other than for cleaning and maintenance, particularly if they are in upper floor levels





Example design option for one bed open-plan dementia specialist apartment

## SECTION 6: LIGHTING DESIGN FOR PEOPLE WITH DEMENTIA

**The Social Care Institute for Excellence (SCIE) suggests that: -**

*People with dementia need to see their environment to help make sense of it and to make the most of their remaining abilities. Effective lighting can help people with dementia see where they want to go and to identify spaces, rooms, equipment and signs. It helps them to see other people's faces and body language, to enjoy recreational activities, to join in everyday routines, and to enjoy the changing seasons. Poor lighting will substantially reduce a person's ability to do all these things. It can also contribute to accidents, particularly falls, and cause unnecessary stress (for example, being frightened by misinterpreting shadows)*

### Ageing and impaired vision

Ageing eyes need twice as much light as young eyes – and people living with dementia need even more. For older people, contrast is reduced, and some colors are hard to see. Good lighting and design can make the difference between seeing and not seeing for older people with impaired vision and between comfort and discomfort. A person living with dementia has difficulty making sense of or recognising what they see – if they can't see things physically as well, it is twice as hard for them as anyone else.

*“Maximising natural light is not only beneficial for seeing in general, but also gives important information about the time of day. Poor lighting can increase the incidence of hallucinations – especially if this creates lots of shadows. It is therefore important to be able to control both natural and electric lighting to prevent sharp variations in lighting levels, avoiding excessive brightness and shadowed areas. Blinds can be useful for diffusing strong daylight, whilst for nighttime a simple bright central light source with carefully directed task lights (making sure that these don't shine in your face or create light pools) are best”.*

Care & Repair England - *Making your home a better place to live with dementia*

### 6.1 LIGHTING DESIGN FEATURES

The entrance and reception areas should be bright and well-lit with maximum use of natural light. All areas should have good levels of both natural and artificial lighting supplemented by more localised lighting if required. Natural lighting should be generally controllable, with the use of furnishings to minimise glare and shadow contrasts. Other communal areas and corridors should be bright and evenly lit, the use of sensory lighting which switches on and off as a person moves along the corridor should be discouraged, as a corridor darkening behind someone could cause confusion and distress. In communal areas, the use of non-reflective glass in windows is preferred to

avoid mirror-like reflections. External lighting should be evenly distributed to avoid pools of bright light and deep shadow contrasts.

The Thomas Pocklington Trust is a leading provider of housing and support services for people with sight loss and a major funder of social research about sight loss and suggests that

*“Good lighting can make the most of sight by increasing contrast and clarity, making it easier to carry out everyday tasks. It can help you stay independent, move around your home easily and safely, continue with, or take up hobbies and interests and help you stay involved with life around you.*

*General lighting should give even illumination, avoiding shadows and dark areas. Brightness levels should be similar in adjacent rooms to avoid your eyes having to adjust when moving between well-lit and significantly darker areas.*

*Good lighting can make your home safer too. Poor lighting on steps and stairs can lead to falls, slips and trips. Simple improvements in the kitchen, especially over work surfaces and cookers, can reduce the risks of cuts, scalds and burns. And in the bathroom, appropriate lighting can make all the difference with personal hygiene and care”*

*And that in kitchens*

*“Additional lighting can be fitted behind a pelmet underneath wall cupboards. This increases light where you need it while shading the bulb from your eyes. Lighting can be plugged into an electric socket or wired into the mains. Lights over a hob are sometimes built into the cooker hood”*

## **What is effective lighting?**

Effective lighting involves a combination of increased light levels, good contrast, minimising glare and avoidance of sudden changes in light levels and good color definition. Quality lighting is a vital component of good dementia-friendly design.

## **Valuing daylight**

Daylight should be used wherever possible because it delivers good colour interpretation and it's free. It is important to make the most of windows and doors that bring in light. Doing simple things such as cleaning windows regularly, opening blinds and moving furniture blocking natural light can make a difference. Being out in daylight is very important for improving mood and body rhythms, increasing vitamin D levels and promoting sleep at night. Balconies and courtyards can be valuable spaces for this.

## **Managing light sources**

Sunlight can be managed with blinds, curtains and external shading devices. Use of a range of artificial lights can help to reduce glare with the main, centrally positioned lights, wall-mounted lights and freestanding lamps.

Having more light fittings is better than having fewer brighter ones. Indirect lighting via the ceiling is good and local lighting should be adjustable and movable as needed.

## **Warning about low-energy lights**

Be careful about where you use low-energy lights – they take a long time to get up to the right light level. This makes them dangerous to use in stairwells as the person may switch on the light and start to climb up or down before the light is bright enough to see. Bulbs should be changed frequently, even if they are still working, because over time they give out less and less light.

More detailed information is available at.

[Enabling Environments](#)

## SECTION 7: MEANINGFUL OCCUPATION AND ACTIVITY

People living with dementia require a high level of dedicated support and meaningful occupation. There are a number of success stories of people moving into specialist extra care housing late on in their condition where design features support them to orientate quickly and where support is tailored to meet their social and emotional needs as well as their physical needs.

As a person's dementia develops, it is likely to have an impact on some of their abilities; however, there should still be lots of things that the person can enjoy doing, both individually and with others. Maintaining existing skills, as far as possible, can give the person pleasure and boost their confidence. For this reason, it is important to help them find activities that they enjoy doing that can continually adapt to meet the person's changing interests and needs throughout the illness.

The word 'activities' is often associated with structured group activities, such as bingo or exercise classes, but not everyone enjoys this type of pursuit. In fact, many beneficial activities are the simple, everyday tasks that many of us take for granted, which may be enjoyed as a solitary pastime, in pairs or small groups. Simple activities such as taking a walk, polishing a pair of shoes, listening to the radio or looking after a pet can help give pleasure and bring purpose to the day.

What is good for someone living with dementia is often good for those who spend time with them too. Through helping maintain the interests of the person living with dementia, family members and carers may be able to follow their own interests too. Keeping occupied and stimulated can improve quality of life for the person living with dementia as well as those around them.

### Benefits to the person living with dementia: -

- remaining physically and mentally active can have a significant impact on a person's wellbeing. It can provide a welcome distraction from the stresses of the illness and can help the person focus on the positive and fun aspects of life
- carrying out simple everyday tasks can help the person living with dementia feel better about themselves by providing a structure to the day and a sense of achievement
- some types of activity can help the person living with dementia to express their feelings - for example listening to music or writing something down

### Benefits to loved ones and carers: -

- boredom and frustration are the two most common causes of challenging



behaviour in people living with dementia. If a person living with dementia is occupied and stimulated, some of the behaviour that those around them find most difficult may lessen or even stop altogether

- sharing an activity that both parties enjoy may bring them closer together and help them find new ways to relate to each other
- discovering new ways to stimulate a person living with dementia can be satisfying and may enable those around them to think differently about their caring role

### Finding suitable activities

If carers and staff want to help someone living with dementia take part in activities, they should talk to them about which activities they might still enjoy and that they could achieve within their current capabilities. Try to find imaginative ways to adapt their activities to their changing capabilities and moods.

It is easy to assume that people living with dementia will inevitably lose everyday skills and become dependent on others. With time, dementia can affect a person's skills; however, the degree of impairment will vary from person to person. It is important for people living with dementia to remain as active as possible. Being active helps people living with dementia to feel good about themselves.

People living with dementia need to continue carrying out as many of their previous activities as independently as possible, in order to retain their skills. Doing things for themselves will enhance their physical, social and emotional wellbeing, through the preservation of their dignity, confidence and self-esteem.

When carers and staff spend time supporting a person living with dementia, they need to encourage them to do whatever they can for themselves, and to offer only as much help as they need. This is not always easy - not least because it may be frustrating watching something being done slowly when carers/staff could do it more quickly and easily for them. Even if the person living with dementia is struggling with a task, carers and staff must try to avoid the temptation to take over. If they do, the person living with dementia may lose confidence and are likely to cope less well.

### Offer help and support sensitively

As the dementia progresses, the person living with dementia may find certain tasks increasingly difficult, while others may remain manageable for much longer. By helping sensitively, carers and staff can offer support while enabling them to do what they can for themselves. Carers and staff will need to adjust the level of help that they offer, so that the person living with dementia can continue to make the best use of their remaining skills.

There are tips that carers and staff can use that will help them to provide care and support sensitively, for example

- breaking the task down into sections i.e. the person living with dementia may find it easier to continue dressing themselves if carers and staff put clothes out for them in the order that they need to put them on, or the carers and staff could pass the next garment to the person, holding it out ready for them to grasp at the right place, or by encouraging them to put their clothing on over their head before straightening it down for them. Even if the person living with dementia can't complete a full task, carrying out one or two steps of it – particularly the final step - can give them a sense of achievement
- carers and staff must make sure that any reminders or instructions are simple, using short sentences, with gestures and body language to add meaning
- being tactful is essential, if carers and staff try to imagine that they are the person receiving help, and speak in a way that they would find helpful if they were in their position
- doing things together can be beneficial, such as folding clothes or drying dishes and integrating opportunities to do things into their daily routine
- carers and staff must make sure that the person living with dementia doesn't feel that they are being supervised or criticised in anyway. This means monitoring the tone of their voice as well as the words that they are using

When the dementia is at a more advanced stage, carers and staff can try pointing, demonstrating, or guiding an action rather than giving a verbal explanation. For example, the person living with dementia may be able to brush their own hair if they are handed the brush and the care and staff start by gently guiding their hand, using their voice to make reassuring and encouraging sounds rather than using actual words.

#### Make sure the person feels safe

Feeling safe is essential for our sense of wellbeing, but for a person living with dementia the world may feel like an unsafe place for much of the time. Most of us can only imagine how frightening it must be to experience the world in this way.

Carers and staff must:

- respond to how the person is feeling at that very moment
- be reassuring, and avoid confronting them with distressing reminders or tasks

- remember, the more they can help the person living with dementia not to feel anxious and stressed, the more likely the person living with dementia will be able to use their skills to their best advantage

### Use of memory aids

Carers and staff can use memory aids and other reminders to help the person living with dementia to use their skills for longer. These may be of most help in the early to moderate stages of dementia when the person is better able to understand the message and to act upon it.

Suggestions can include:

- labelling cupboards and drawers, perhaps using pictures rather than words - for example, a photo of a cup and jar of coffee, a large calendar showing the day, month and year
- providing a notice board for messages
- using notes stuck by the front door

*Leading the fight against dementia: Maintaining everyday skills, Alzheimer's Society*

## **7.1 DESIGNING MEANINGFUL ACTIVITIES FOR THE OLDER ADULT**

Normal day to day activity should be encouraged and supported as much as possible. Therefore, it is worth considering whether a domestic kitchen should front the full catering kitchen in an ECH scheme. This would enable residents to be involved in food preparation, table setting and clearing, baking etc if they wish to do so. Sideboards and dressers should be provided in the restaurant, so people recognise where crockery, cutlery etc is kept.

Other facilities should offer similar opportunities to people such as the hair and beauty salon, the shop, library etc. Being supported to do work in the gardens is also important as this encourages people to exercise and have time in the fresh air.

Facilities for art, craft and general recreational activity are very important so that residents can both as an individual and as a group, participate in meaningful activities. This may include wireless access for recreational technology activities.

Recreational areas should incorporate easy and visible access to outside spaces with the provision for residents to engage in light gardening.

Ideally, a large room that can be used for social occasions should be incorporated into plans.

Fully accessible toilet facilities should be near at hand and visible from a seated position and/or well signposted in recreational areas.

Furniture incorporating shelving and attractive display areas should be provided for residents to display their work.

If the recreational areas are to be fitted with kitchen areas the worktops and sinks etc should be at a suitable height for all users including wheelchair users and those with reduced mobility.

Ellis Waller, a Gerontologist from the University of Southern California, has been working in the gerontological field since 1977, as an aging specialist. She is currently the director of Care Connections, a respite care centre for individuals who are frail or who have slight memory impairment. In addition to providing care-management services, she also teaches and consults with organisations that provide health care and housing services for the elderly. In her training modules, she suggests that: -

*The philosophy of designing meaningful activities is extremely important. Activities for the person with Alzheimer's should be age appropriate. The philosophy of activity planning can be best summed up by the following: -*

*Activity's purpose is not to kill time,  
but to make time live,  
not to keep a person occupied,  
but to keep him refreshed,  
not to offer an escape from life,  
but to provide a discovery of life.*

**The types of activities which provide meaning in our lives include all of the following: -**

- intellectual activities - activities which stimulate thinking or memory
- creative activities - such as music or art which can enhance memory
- personal care activities - such as dressing, brushing one's teeth, or brushing one's hair
- functional activities - such as setting the table, folding washing, sweeping the floor washing windows
- physical activities - such as walking, chair exercise
- social activities - having refreshments, or caring about others in similar situations
- spiritual activities - singing hymns or listening to music

### **The purposes of activities are as follows: -**

- enhance the quality of life
- maintain physical wellbeing
- encourage socialisation
- encourage expression of feelings
- maintain connections with the outside world
- bring some fun into the day
- encourage use of remaining abilities
- encourage independence and promote self-esteem
- provide intellectual stimulation

It is important that the types of activities selected are age appropriate. Helping people feel empowered by giving them control; over the subject they paint, the games they choose or the activity they participate in, is essential for maintaining self-worth. On the other hand, it is important to encourage individuals to participate in activities that they may be reluctant to do, because of fear of feeling foolish. Developing a safe and secure environment, where the person is cared for, should help him/her feel safe and secure, and should encourage individuals to enjoy activities that they might not otherwise try.

More information and training modules are available at: -

[Meaningful activities for a person with dementia - Dementia UK](#)

### **The use of doll therapy for people living with dementia**

There are differing opinions on the use of doll therapy for people living with dementia. Research suggests that on one hand it can be beneficial and helps to reduce challenging and negative behaviour and can have a comforting and calming effect on the resident, on the other hand some research suggests that doll therapy can be seen to be patronising or demeaning.

If the use of doll therapy is to be considered, it should be remembered that this type of therapy is not suitable for everyone and that it is likely to be suited to women more than men, although its use for men should not be ruled out.

Certain factors should be taken into consideration if attempting to use this type of therapy: -

It is important that a doll isn't given directly to the person. Rather, it should be left somewhere, on a table or sitting in a chair for example, somewhere that it will be found. This way the individual can make the choice to provide care for the doll, not feel that they are being given the responsibility to do so, which could cause anxiety or result in the doll being rejected.

For doll therapy to be effective, it is recommended that you use a doll that is as lifelike as possible. Introduce the doll in the middle stages of Alzheimer's/dementia, or even in an earlier stage, depending on the individual. Often when introduced later, the person fails to or has a more difficult time making a connection with the doll. Once the connection has been made, the rest is easy. It's a self-administering therapy.

The nurturing instinct is strong. This is a big part of the reason that doll therapy is effective, but it can lead to some problems that should be watched for when introducing dolls as therapy. In community settings, ownership issues have led to arguments between residents. Anxiety can result from dolls being mislaid. The first two of these concerns can usually be minimized by recognizing their potential and by re-directing the resident's attention if the problem arises and before it has had a chance to escalate.

If you see that it is being more problematic than beneficial, discontinue it in favour of some alternate non-pharmacological therapy.

*Doll Therapy for Alzheimer's Disease, Best Alzheimer's Products*

## 7.2 IMPROVEMENT AND MAINTENANCE OF QUALITY OF LIFE

In all aspects of residents' daily living activities, their rights to choose when and if to participate in the opportunities must be respected. It is, however, acknowledged that people living with dementia may need specific activities and/or be actively encouraged to participate in pastimes and events to avoid becoming isolated.

It is essential that when completing a resident's care and support plan it reflects the support they need to access social activities and events, stating exactly what support they need so that they do not become socially isolated. The level of support can simply be checking on someone or escorting them to an activity and helping them to take part in it.

The activities do not necessarily need to be planned and time-specific and may be simple household tasks or hobbies and pastimes that they have done as part of normal day to day living. Talking to residents' families, friends and advocates will help staff to identify activities that people have enjoyed taking part in previously or might get pleasure from now.

Opportunities to participate in activities must be provided around the needs of individuals. A wide range of daytime activities should be available to enable residents to maintain existing interests and skills and offer them the opportunity to acquire new ones. Assistance should be provided to those residents who need it in order to be able to participate in these activities. They are likely to include a range of one-to-one as well as group activities.

A regular programme of activities and events should be encouraged to promote relaxation and provide entertainment. Support and assistance must be provided so that residents can also make use of ordinary community facilities outside of the scheme.

Residents should be supported in maintaining their network of relationships with family and friends and be offered opportunities for developing new social contacts.

Residents should also be supported and encouraged in helping one another, family members and friends. There should be opportunities offered to contribute their skills and experience to the life of the wider community. They should also be enabled to participate in discussions concerning the management of the scheme through resident forums or committees.



## SECTION 8: CARE AND SUPPORT DELIVERY

### 8.1 GUIDELINES FOR SERVICE DELIVERY

North Yorkshire Council has developed a model of care and support within ECH. A key principle of the model is that background care and or support (known as **flexiCare**) is available to everyone within a scheme and there is a charge per unit for this service. In addition, people who are assessed as having further care and/or support needs receive a Personal Budget in the form of an Individual Service Fund, which can be used to purchase care and support either with the provider of the background support, or with a provider of the resident's choice. Further information about the **flexiCare** model is available in North Yorkshire Councils Partnership Service Protocol

The care and support must be provided in a manner which offers confidentiality, respect, dignity and privacy and does not erode the resident's capacity for self-care, or the contribution made by family carers. Key to providing the best possible support is the assessment, care and support planning and review process.

Each resident living in an extra care housing scheme will be respected as a unique individual, with recognition being given to his/her particular physical, psychological, social, emotional, cultural and spiritual needs.

Assessment, care and support planning and reviewing are key aspects of best practice and documenting the service received by individuals is vital. The way in which care and support services are documented will evidence what is occurring for the individual as well as demonstrating whether person-centred care is integral to the service provided.

#### **Key indicators of best practice suggest that: -**

- a full assessment is undertaken prior to a service being provided
- evaluation and reassessment are on-going
- all relevant documentation used by the organisation demonstrates that the individual is fully involved
- cultural needs are appropriately considered
- wellbeing for the individual is actively promoted
- the language used will be acceptable to the person receiving care
- care and support plans are used as communication tools, evaluation is meaningless in the absence of well-documented care and support
- a key worker system matches individuals and staff

- relatives (and significant others) feel involved and supported

*Key principles of person-centred dementia care, National Care Forum.*

## 8.2 SUPPORTING PEOPLE WITH DEMENTIA

In 2011 the Department of Health in conjunction with Skills for Health and Skills for Care produced a training called Common Core Principles for Supporting People with Dementia.

*This guide presents eight Common Core Principles for Supporting People with Dementia. They can be used to enable workforce development for any member of staff working in health or social care with people at any stage of dementia, from the earliest signs to the fully diagnosed condition. The common core principles are relevant to every setting and provide a basis for a general understanding of the condition. They aim to build workers' confidence in adapting their actions and communication in order to respond appropriately to the person with dementia. Signposting to resources and further reading has been included at the end of the guide.*

Although the guide is written primarily for the health and social care sectors, the principles and supporting information will also be of interest to those working in any situation where people interact with those living with dementia. The principles can be applied to any customer-focused provision, with equal relevance to those working in settings such as shops and banks, as well as public sector settings such as library, education and housing services.

*“The principles have been written on the assumption that the workforce supporting people in the later stages of dementia will have received specialist training and support.”*

*Common Core Principles for Supporting People with Dementia. A guide to training the social care and health workforce, Department of Health, Skills for Health, Skills for Care, (2011)*

The guide is available to download at:

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_127587.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_127587.pdf)

## Best practice examples:

There is a lot of information available and many examples of methods to support people living with dementia, for example the SPECAL method (Specialised Early Care for Alzheimer's) and Dementia Care Mapping. Both of these methods particularly focus on providing person-centred care and support to people living with dementia and are simple and easy to put into practice.

### Contented Dementia Trust - *SPECAL method*

The Contented Dementia Trust, formerly known as SPECAL, is an independent charitable organisation with an innovative approach to the care of people with dementia.

Their vision is:

*“a world where a diagnosis of dementia is no longer viewed with fear, to ensure that the person with dementia, and their carer, can lead as close an approximation to the life they would have wished to live without dementia and to ensure that the impact of the specific memory change experienced by people with dementia is clearly understood and taken into account in the design and planning of dementia services”*

Their practice-based approach is rooted in:

- universal person-centred care
- the subjective experience of dementia, as explained by the SPECAL Photograph Album
- the need for fully individualised care which works positively with each person's dementia as a key resource

The SPECAL method is based on a unique understanding of what the experience of dementia is all about, from the perspective of the person with the condition.

They use a simple analogy – the SPECAL photograph album – to explain:

- how normal memory works
- what happens to all of us as we grow older
- a single significant change that occurs with dementia

The SPECAL Photograph Album understanding of dementia enables carers to adapt their behaviour to take account of the dementia.

The SPECAL method sees dementia as a disability that can be managed with remarkable success, not as an irreversible medical condition to be defeated.

SPECAL sense begins with three Golden Rules:

- Don't ask direct questions
- Listen to the expert – the person with dementia – and learn from them
- Don't contradict

These Three Golden Rules run contrary to common sense communication styles which are taken for granted when dementia is not an issue.

1. Don't ask direct questions:

Avoid asking any direct question that requires the person with dementia to search for factual information that may not be stored in their album. They are already aware of their disability. Asking them to search for facts they may not have will merely increase this awareness, causing them unnecessary distress and potential trauma.

It is surprising how much information you can gather without asking direct questions!

2. Listen to the expert (the person with dementia) and learn from them:

Listen to the questions the person with dementia is asking and consider very carefully what the best answer might be from their perspective rather than your own.

For people with dementia, feelings are more important than facts. It is crucial that the information they receive generates good feelings for them.

- having a record of good feelings, yet not knowing why, is one thing
- having a record of negative, possibly traumatic feelings with no explanation as to why, is quite another

We owe it to the person with dementia to avoid leaving them with anxieties that they cannot, only moments later, explain. So, we must search for the information and the language that is most acceptable to them. Once we have found the best answer to their most frequent question, this form of words should be used consistently by everyone coming into contact with the person. This may not be common sense, but it is certainly SPECAL sense, and it increases confidence all round. Carers using the SPECAL method find that the person's anxious questioning gradually subsides.

3. Don't contradict:

Do not argue with the person with dementia about which page or which photograph they are choosing to use in their album.

They are increasingly likely to use intact memories from their pre-dementia past, in order to understand what is happening around them in the present. The rest of us

need to avoid disturbing the sense they are making and start where they are at. We need to take careful note of the language they use, so that we can follow them, rather than expecting them to follow us.

The Three Golden Rules may seem counter-intuitive at first, but when they are used by everyone coming into contact with the person with dementia, the benefits quickly become self-evident, and life will be much easier.

More information about the SPECAL method is available at:

<http://www.contenteddementiastrust.org/2011/11/21/never-too-late-again/>

### Dementia Care Mapping

Dementia Care Mapping (DCM™) was developed by Professor Tom Kitwood and the Bradford Dementia Group at the University of Bradford. Dementia Care Mapping is designed to help professionals to observe the behaviours amongst people living with dementia in a communal setting. It is designed as a process that observes life through the eyes of a person with dementia. The mapping involves tracking the state of residents' wellbeing and the nature of social interaction to see how they respond (positively and negatively) to events that happen to and around them. It usually involves the 'trained mapper' observing up to five people with dementia, continuously over six or seven hours and recording events which take place within that period, while also assessing the staff who deliver that care and identifying staff training needs. After each five-minute period, the mapper will note the behaviour, mood and engagement of the person/s they are observing. All interaction is recorded, including personal enhancers (any interaction that has a positive experience on the person and their wellbeing) and detractors, which have the opposite effect. Anything that provokes a strong reaction is recorded as highly enhancing or highly detracting from wellbeing. This raw data is then analysed by the mappers and recorded in a recognised format.

Once the initial exercise has been completed, the mappers return to the care home to give staff feedback on the results. This is done in a variety of ways including role play, PowerPoint slides, written presentations and group discussions. Staff members are encouraged to take ownership of the report, and with the support from their managers, look at how they can improve the quality of care, interactions and wellbeing of the people living in the home.

Dementia Care Mapping Supported Living (DCM-SL™) is an observational tool based on Dementia Care Mapping™ that has been specifically designed and tested for acceptability of use in supported living contexts (Surr et al, 2009). This includes home support/care/domiciliary care, extra care housing, supported living, retirement communities and any settings where people with dementia are observed in their own

home or private, individual living space.

More information about dementia care mapping DCM™ available courses is available at: -

[Dementia Care Mapping - Training and consultancy - University of Bradford](#)

There is a large amount of useful information available on the internet which includes some good practice guidance on promoting peer support amongst people living with dementia in Extra Care schemes. The Housing LIN Case Study 80, *Doing it for ourselves: Self-help groups for people with dementia living in extra care housing schemes*, highlights an on-going evaluation of three peer support groups that have been set up in EC schemes in London:

[Doing it for ourselves: Self-help groups for people with dementia living in extra care housing schemes - Resource Library - Resources - Housing LIN](#)

The links below provide information from The Mental Health Foundation about the above evaluation of the peer support groups:

<http://www.mentalhealth.org.uk/our-work/research/dementia-self-help/?view=Standard>

The Housing LIN also have provided some very useful resources on using ICT for people with dementia for a wide range of activities:

[ICT and Dementia - Housing LIN](#)

### **8.3 CARE AND SUPPORT ASSESSMENTS**

Community Care Assessments (an assessment of a person's personal care and support needs undertaken by an Adult Social Care Assessor from the County Council) will be undertaken for all residents. Reviews will be undertaken no later than six weeks after a resident's move and every six months subsequently with a formal review with all parties attending not less than annually. Anybody can request a review. Urgent reviews will be undertaken within 72 hours. It is the responsibility of the care/support provider to ensure that a review is undertaken.

There must be a risk assessment undertaken as part of the community care assessment prior to the service user moving into the scheme. Individual care will be drawn up in consultation with the resident, the family and carers. They will reflect the assessed care and support needs of the resident. Each service support plan will be reviewed regularly, that is a minimum of quarterly and/or after any significant change in the resident's needs. Each resident will be encouraged where appropriate to participate in all decision-making processes and express their views. Where this is not possible a relative/advocate or representative should be available.

In all aspects of service delivery, the needs of the whole person (i.e., physical, psychological, social, emotional and spiritual) will be considered and taken into account, building on the original assessment information. This will require scheme staff to spend time on gaining an understanding of the individual's life history, personality, mental and physical health, relationships, attitudes and aspirations. The planning or provision of the care and support service will always be approached from the resident's perspective and maintain a person's normal behaviour, in line with their personality and characteristics before they developed dementia.

Services will be designed to achieve the maximum rehabilitative effect, utilising the support provided by North Yorkshire Council's Short Term Assessment and Reablement Team (START) who will maximise a person's ability to maintain their independence. It is important that where they have the ability, residents are supported to carry out tasks for themselves, even though it would be quicker for staff to undertake tasks directly. As well as assistance with hands-on physical rehabilitation, appropriate aids and equipment will be available, assisting in the learning or re-learning of skills and techniques necessary for independent living, the provision of encouragement and support to rebuild confidence or self-motivation, etc.

A range of preventative services should be available to residents to assist and to preserve or promote their own health and wellbeing. These should include support and advice and opportunities for maintaining physical fitness, good nutrition and a positive attitude towards ageing. Services could include other therapeutic activities including complementary therapies.

Services provided will be flexible and responsive to the wishes of the individual residents. Loss of control over the person's order of day-to-day activities has been found to increase dependency. As far as is practicable, residents or their representative will be able to exercise control over the timing and type of assistance they receive with tasks that they cannot do for themselves.

A close working relationship between scheme staff, care providers, assessment teams, GPs, primary health care teams, pharmacists, health trust staff and the voluntary sector etc, must be established and maintained to ensure that the health, independence, and the mental and physical ability of residents are optimised. Specialist medical staff may need to contribute to the assessment process. Links must be developed with all aligned services to ensure advice and support when needed. Support plans, a shared document detailing people's care, support and activity arrangements will be kept in the resident's flat. Only the resident's authorised personnel and family members with the resident's consent will have access to them.

Knowledge that staff have about an individual is also to be treated as confidential. This information will only be passed on to other staff where it is necessary for the safe and well-managed provision of care and support or where there is a safeguarding issue when it will be shared with the relevant authorities. This handover of information will be done in private and with a professional manner.



Where written or computer records are held, the provisions of the Data Protection Act will apply. Staff and residents will be advised that an individual has the right to see the information that is held that relates to them. All records kept will be made with this in mind. Residents' access to everyday opportunities and facilities will not be restricted because of their needs or disability.

Residents will have the support and assistance they need to access everyday opportunities and facilities. Every resident will have access to an advocate if required.

Residents, their family and/or their representatives/advocates will have full information on the services and choices available to them.

Care staff will be available within the scheme 24 hours a day to provide personal care and support services in line with the agreed individual support plan. However, staff should only provide these services where it has not proved possible to enable the residents to undertake all or part of the task for themselves.

Each resident will have a flexible care and support delivery programme based on the assessed support plan, which identifies targets and outcomes, agreed by the resident or their representative, care provider staff, scheme staff and the Health and Adult Services/Health Assessor.

The support plan will be reviewed as a minimum every three months by provider staff with the resident and their representative. The care provider, ideally, should operate a key worker scheme, (assigned to work with the resident and their relatives to establish information that helps in offering care and support appropriate to their needs).

Day to day changes in the needs of individuals will be monitored and responded to by the care provider in liaison with the care and health assessors for major changes. A shared approach should be adopted, where staff work with residents and their family carers to carry out agreed tasks.

The scheme will have an emergency call system that enables residents and staff to summon assistance in an emergency. Response to such calls will be time limited and form part of the scheme's internal quality assurance system. It is recommended that response times are monitored electronically through the call system.

Staff must be familiar with their own organisation's Challenging Behaviour Policy and follow correct procedures in managing this behaviour.

The care provider will not provide care requiring the skills of a qualified nurse unless there are registered services incorporated into the housing design model of the extra care scheme, for example where a scheme has been built with different units which may include general extra care, dementia care or other specialist services and/or accommodation. Staff should work with the district and community psychiatric nursing services to support residents. However, if continuous nursing or specialist medical care is required that cannot or will not be delivered appropriately in the scheme; a

community care assessment will be carried out to establish whether alternative care arrangements need to be made. Assessors, residents and their families should work together to ensure that residents are in the most appropriate accommodation for their changing needs and that services are flexibly responding to those changing needs.

## SECTION 9: STAFFING

Staff are any organisation's most valuable asset. The organisation is responsible for creating a culture that enables staff to reflect, to learn and to develop. It is essential that a person-centred approach to dementia care is consistently applied throughout the whole organisation.

### Key indicators of best practice:

- recruitment procedures and practices reflect a culture and style of the organisation which supports a person-centred approach
- as much importance is given to staff retention as to staff recruitment
- a focus on abilities, promoting appropriate attitudes and enabling staff to contribute fully to the provision of care
- valuing diversity
- staff have a non-judgmental approach and a positive regard for each other and for those they care for
- systems are in place for professional supervision and support
- appropriate learning and training opportunities are provided

*Key principles of person-centred dementia care, National Care Forum.*

The recruitment and selection process of care provider organisations should identify key values and attributes that staff will need when working with people living with dementia including the ability to empathise and understand the complexities around the condition and appreciate the difficulties faced by people who are living with it.

Staffing levels in extra care housing should not only reflect the physical needs of individuals, but also the social and emotional needs. Staff should ideally receive comprehensive and ongoing training in the following areas: -

- person-centred approach to working with people living with dementia
- the role of the family/carers in supporting residents and informing staff
- a knowledge and understanding of the physiological and psychological effects of dementia
- skills in the management of relationships
- stress recognition and management, including loss/grief counselling
- equal opportunities
- management of behaviour that challenges the service
- assessment and care planning

- communication skills
- rehabilitation
- an understanding of housing issues, e.g., housing benefits and welfare rights

Staff should clearly see their role as enablers and facilitators and, only when it is clear that a task cannot be completed, intervene. However, whilst rehabilitation is a positive approach, staff must have the skills to understand when this approach is not appropriate.

The person who is living with dementia usually knows what they want but may have trouble expressing their needs. It is essential that staff listen to the person living with dementia, learning from their behaviour, language and other communication methods about what they like, what they want to do and what is important to them and then respond appropriately with the care and support that they provide.

Attention should be paid to ensure that opportunities exist for staff to support the residents to participate in varied social activities. Opportunities should also be provided for worship in a manner appropriate to the individual. Staff should encourage and support residents to participate or access these activities.

Staff should be creative and encourage residents to explore and try out new things. If something works, repeat it, if something does not work, try something different, or try again in a different way. Staff should stay active in developing opportunities for each person living with dementia, rather than responding to crisis and things that go wrong.

Staff working in the scheme will be committed to the service and learn more about dementia. They will promote friendships between residents, relatives and members of the community.

## SECTION 10: MEDICATION

Staff training is essential to the successful implementation of the care provider's medication policy. This training must include input from a pharmacist and shadowing trained staff. Different organisations have their own policies for medication administration, and those policies must be observed where applicable. The guidelines listed below are a starting point for a comprehensive medication administration process.

The starting point assumes that people should be encouraged to manage their own medication, however, residents in extra care housing, particularly those living with dementia, may be unable to take responsibility for their own medication. A risk assessment will be undertaken, and its outcome recorded in the community care assessment and the care and support plan. Re-assessment may be triggered by an inability to follow a medication routine because of either physical or mental frailty. Strategies for coping with this situation could range from simple supervision of self-medication to the provision of a storage facility that complies with the regulations for all classes of drugs.

Residents who need help with medication usually fall into the following broad groups: -

- those who require prompting and supervision to self-medicate. Medication should be stored wherever it is most accessible to the resident in his or her own home unless as otherwise agreed on the care and support plan
- people with any form of dementia or memory loss may be at risk of overmedicating. In this situation medication may need to be stored securely in their own flat. This must be agreed in the care and support plan
- people whose mental health condition leads them, on occasion, to misuse their medication (e.g., hoarding/hiding/evading or disposing of their medication) may need to have medication stored securely. This must be agreed in the care and support plan

Below is a non-exhaustive list of possible ways of assisting residents where difficulties with medication have arisen, pertaining to prescribed and/or non-prescribed medication. In the case of non-prescribed medication, checks will be made in consultation with a GP and/or Pharmacist for compatibility.

Below is a non-prioritised list of possible solutions. Use of any of them should be discussed with all involved and recorded on the support plan: -

- the use of dosset boxes to assist with either self or assisted medication. If assistance is given then the provider must sign a record
- each flat has a locked medicine cupboard – staff will follow a set procedure for administration

- ear and eye drops to be administered by staff and signed for. A district nurse or health professional will train staff before they undertake this task
- that, within each flat there is a locked container within a locked medicine cupboard for the safe keeping of controlled drugs. Staff will follow a set procedure for
- administration of these medications
- a member of staff administers liquid and PRN (pro ne rata medication, commonly used in medicine to mean "as needed" or "as the situation arises") from the original containers in accordance with instructions as outlined by the GP and Pharmacist
- staff remind residents to take their medication which is in their flat
- residents or their representative re-order medication as and when required **OR** staff are responsible for re-ordering and obtaining prescriptions/dossett boxes and ensuring that adequate medication is held for that resident
- extra training will be necessary should a resident require assistance with invasive treatments/injections of e.g., insulin

Completed records must be held on the resident's file. The scheme manager/care provider manager must be made aware of any difficulties in implementing the medication strategies in the care and support plan and is responsible for overall monitoring.

In the case of any changes to the medication regime, the resident should be encouraged to return un-used medication to the Pharmacist. Where workers have taken responsibility for administration of drugs then the staff will take responsibility for this.

## **SECTION 11: SAFETY AND SECURITY**

Resident call systems will be fitted, and they should be easy to identify in toilet facilities. These will be in both the communal areas and within the private apartments.

It is recommended that future extra care housing schemes are fitted with a fire sprinkler system but where this is not provided the fire safety provision and relevant requirements will be checked regularly.

Where already fitted, hose reels and extinguishers should be located to reduce residents' anxiety and scope for tampering.

Windows should generally be able to be opened but have restrictors to limit opening other than for cleaning and maintenance on levels other than the ground floor.

The use of technology is of paramount importance to ensure unobtrusive safety features are incorporated into the designs for schemes where people with high support needs are living, this includes both communal areas and within the private apartments.

An assessment must be carried out for each resident to ascertain which equipment might be beneficial for their personal safety and security. North Yorkshire Council has devised a basic telecare specification for extra care housing schemes where people with high support needs will be living (see section 12). Wanderguard systems must be fitted to all external doors and a full assessment carried out for a particular resident's suitability to benefit from the use of this equipment.

### **11.1 MANAGING RISK**

It is important that a positive approach to risk taking is adopted in schemes where people living with dementia are residing. Appropriate methods of care and support along with assistive technology can support a person living with dementia to live independently and safe from risk and harm, without having to put physical barriers in place. North Yorkshire Council support schemes that do not use progressive privacy excessively to restrict movement of people living with dementia. This approach will require other methods of security for the person's apartment to be considered, for example, a door sensor or specialist door locking systems.



## SECTION 12: ASSISTIVE TECHNOLOGY

Dementia makes day-to-day life more difficult. Little things like mislaying keys, forgetting to turn off the taps or leaving the gas unlit can prove frustrating or even create hazards. The following information looks at technological developments that can help make life easier for people living with dementia and their carers in certain situations. It also suggests the steps to take if you think that you, or someone you are caring for, could benefit from some of these devices.

The phrase 'assistive technology' is often used to describe products or systems that support and assist individuals with disabilities, restricted mobility or other impairments to perform functions that might otherwise be difficult or impossible. ([Assistive technology: definition and safe use - GOV.UK \(www.gov.uk\)](https://www.gov.uk/guidance/assistive-technology-definition-and-safe-use))

This includes equipment and devices to help people who have problems with: -

- speaking
- hearing
- eyesight
- moving about
- getting out and about
- memory
- cognition (thought processes and understanding)
- daily living activities, such as dressing and preparing meals
- socialising
- managing continence

Assistive technology ranges from very simple tools, such as calendar clocks and touch lamps, to high-tech solutions such as GPS to help find someone who has gone missing.

### **Assistive technology can: -**

- promote independence and autonomy, both for the person with dementia and those around them
- help manage potential risks in and around the home
- reduce early entry into care homes and hospitals
- facilitate memory and recall
- reduce the stress on carers, improving their quality of life, and that of the person with dementia

*Leading the trend against dementia. Alzheimer's Society.*

**Other equipment available, but not limited to: -**

- flood detector
- bed/chair sensor
- temperature extreme monitor
- light controller
- universal sensors
- fall monitor
- digital display clocks (optional)
- digital display calendars (optional)
- GPS trackers
- Door sensors
- Lifestyle monitoring i.e. Canary system

## SECTION 13: END OF LIFE CARE

In October 2012 The National End of Life Care Programme, with the NHS and Housing LIN produced a resource pack which was

*“designed for anyone who is caring for or giving support to someone with a life limiting condition in an extra care housing setting”. This includes people with any chronic condition such as heart failure or respiratory problems as well as people with dementia. Many people develop general frailty and other health problems as they get older.*

*The idea for the resource pack was a recommendation from extra care housing staff who took part in a service improvement project that Housing 21 and the National End of Life Care Programme jointly undertook in 2008. The evaluation report made it clear that there was a need to improve the knowledge and skills base of staff. The pack is intended to be a practical tool which gives useful information and guidance. It offers advice on simple things that staff can do, questions that should be addressed and helps to identify how and when to access specialist help. Much of the information contained is generic and will be relevant to extra care schemes in different localities. However, some information will inevitably be area specific, for example local contact details for health and community care teams. Where locally specific knowledge is needed, guidance in this pack will help you to find out the relevant information. The pack also contains details on important terminology concerned with end-of-life care and specialist health matters”*

(Published by the National End of Life Care Programme, October 2012)

The full resource pack is available at: -

[http://www.housinglin.org.uk/library/Resources/Housing/Support\\_materials/Other\\_reports\\_and\\_guidance/EoLC\\_Learning\\_Resource\\_Pack\\_Housing.pdf](http://www.housinglin.org.uk/library/Resources/Housing/Support_materials/Other_reports_and_guidance/EoLC_Learning_Resource_Pack_Housing.pdf)

Dementia UK have also published information on End of Life Care for people living with Dementia. Further information available at: -

[Recognising the later stages of dementia and moving towards end of life care - Dementia UK](#)

The information, advice and suggestions provided in this guide are not exhaustive and are collated from best practice research from a range of sources. The guide is designed to give extra care housing and care providers and commissioners an insight into some

of the design features that can best support people living with dementia in extra care housing schemes.

The Guide will be subject to regular review and subsequent updating. This will occur as a result of changes in legislation and standards and feedback from providers and developer partners as well as people who live in the schemes and people who come in to use the facilities and services.

## ACKNOWLEDGEMENTS

The following guidance has been utilised in the development this guide.

- North Yorkshire Council, Dementia Strategy,  
[NYC Bring me Sunshine 68982 Dementia Strategy proof v2 04Oct.pdf](#)
- Alzheimer's WA, Enabling Environments;  
[Enabling Enviroments](#)
- Thomas Pocklington Trust  
[RF design 1 \(pocklington-trust.org.uk\)](#)
- Dementia UK, Meaningful activities for a Person with Dementia;  
[Meaningful activities for a person with dementia - Dementia UK](#)
- Alzheimer's Society – Leading the trend against dementia.  
[www.alzhiemers.org.uk](#)
- Alzheimer's Society, Leading the fight against dementia: Keeping active and staying involved  
[www.alzhiemers.org.uk](#)
- Alzheimer's Society, Leading the fight against dementia: Maintaining everyday skills  
[www.alzhiemers.org.uk](#)
- Opening doors to independence – summary A longitudinal study exploring the contribution of extra care housing to the care and support of older people with dementia, Sarah Valletly, Simon Evans, Tina Fear & Robin Means.
- National Care Forum: Key principles of person-centred dementia care
- Dementia Care Mapping:  
[Dementia Care Mapping - Training and consultancy - University of Bradford](#)
- Better Health Channel, dementia through all its stages.
- The Contented Dementia Trust – SPECAL method.  
[http://www.contenteddementiatrust.org/2011/11/21/never-too-late-again/](#)
- Making your home a better place to live with dementia, Care & Repair England
- Improve the lighting in your home, 3rd edition, The Thomas Pocklington Trust

A pilot study on the use of dolls for people with dementia, Project registered as Service Improvement/Evaluation Project with R&D Department of Newcastle, North Tyneside and Northumberland Mental Health NHS Trust, 2006

- <http://ageing.oxfordjournals.org/content/35/4/441.full.pdf+html>
- *Doll Therapy for Alzheimer's Disease*, Best Alzheimer's Products  
<http://www.best-alzheimers-products.com/doll-therapy-for-alzheimers-disease.html>
- The mental health Foundation  
<http://www.mentalhealth.org.uk/our-work/research/dementia-self-help/?view=Standard>
- Housing LIN  
[Doing it for ourselves: Self-help groups for people with dementia living in extra care housing schemes - Resource Library - Resources - Housing LIN](#)

#### **Disclaimer**

The contents of this document are provided by way of general guidance only at the time of its publication. Any party making any use thereof or placing any reliance thereon shall do so only upon exercise of that party's own judgement as to the adequacy of the contents in the particular circumstances of its use and application. No warranty is given as to the accuracy, relevance or completeness of the contents of this document and North Yorkshire Council, shall have no responsibility for any errors in or omissions there from, or any use made of, or reliance placed upon, any of the contents of this document.