mentaur
caring with commitment

SPECIALIST RESIDENTIAL SERVICES

for people with a learning disability and dementia

Aurora House, Bedford

Dementia & Learning Disability

Assessment

Design Features

Staffing

Care & Support

Acknowledgements

The development of this detailed booklet has been made possible through the inputs of various individuals. Loreto Soto Ponce and Tara Dutta at the Mentaur office have been responsible for conjuring up the design and creative elements. Much of the content surrounding the scientific information and standards of care have been developed by Dr. Shekhar Mukherji, Clinical Director of the service along with Isabel Melo, Operations Director. There have also been various useful inputs from the Area Service Manager and the Manager of Aurora House.

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Lastly but most importantly, we are indebted to the users of the service and their families, for it is through them that care and support transforms from theory to a personalised and practical knowledge base.

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Background

Mentaur has been providing care and support to people with learning disabilities since 1988. Mentaur Specialist Services provides innovative specialist care to people with learning disabilities who have associated needs such as dementia, autism, mental disorder and forensic needs.

Over the years, the organisation has built up a reservoir of knowledge and experience in the area of dementia care. It is this knowledge and expertise which has been brought to bear in the development of specialist residential facilities such as Aurora House.

Aurora House

Aurora House is a small specialist facility in Bedford designed to give seven adults with a **learning disability and dementia** a home which complies with their specific needs and understands their singularity. The service offers a flexible long-term provision that recognises and plans for progression of decline and loss of function.

The cutting-edge design of the home is dementia specific. Along with a sense of space and special sensory features, the house is of a size and proportion consonant with ordinary domestic living. This is particularly suitable for people with a learning disability.

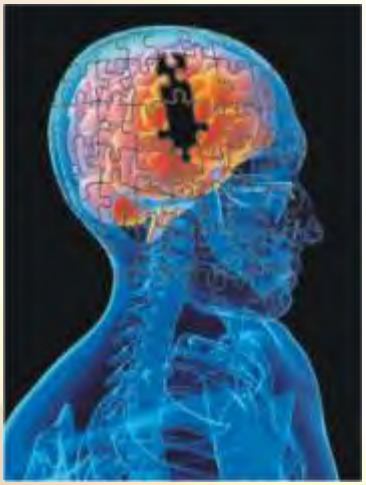
We intend that the people who use this service will be empowered to exert choice and control and push back the perceived barriers to their disability to live a varied and rich life. This includes preserving and developing relationships and skills, person-centred management of risk, local community engagement and pressing for access and rights.

‘You cannot rob me of free nature's grace,
You cannot shut the windows of the sky
Through which Aurora shows her brightening face’

James Thomson, Castle of Indolence, Canto II

Dementia & Learning Disability

* Down's Syndrome & Dementia



With the increase in the longevity of people with a learning disability, including Down's Syndrome, we are seeing a corresponding increase in dementia occurrence. The frequency with which Downs Syndrome occurs has also remained stable.

The statistics speak for themselves. In 1900, people with Down's Syndrome in the U.K. lived, on average, for a heart-rending 9 years. In 1983 this figure had gone up to over 25 years and at the end of the first decade of the 21st century, with community inclusion and better health care, has encouragingly risen to around 56 years.

More than 25% of people with Down's Syndrome now live to an average age of 62 years. Added to this is the fact that dementia in people with Down's Syndrome presents early, sometimes as early as 35 years, with a peak incidence in the first part of the sixth decade of life.

The best estimate is that, in 2010, there are more than 7500 people in the U.K. with Down's Syndrome and dementia. According to some estimates, there may be more than a 1000 people with Down's Syndrome who are developing dementia every year. People with Down's Syndrome over the age of 65 may have a 2 in 3 chance of developing dementia. Almost all those with Down's Syndrome who develop dementia have Alzheimer's disease.

All these factors are quietly conspiring to create a major health problem whose needs are being inadequately met.

* Dementia in Generic Learning Disability

The problem unfortunately does not stop with Down's Syndrome.

It is believed that between 18-25% of people with a learning disability over the age of 65 will develop dementia. This is because dementia is 3 to 4 times more common in older people with a learning disability in comparison with the general population of a similar age.

Again people with a learning disability are living longer.

And dementia tends to present earlier, almost 10 years earlier than expected.

The pattern of causes of dementia in people with a learning disability, who do not have Down's Syndrome, is the same as in the general population. Though Alzheimer's disease remains the most common cause, there are many other reasons why dementia may develop. These different causes and types of dementia may present in fundamentally different ways than are normally seen in Alzheimer's Disease.

Dementia - a Roller Coaster Ride!

Assessment

* Overview of Dementia

Dementia is a chronic disorder of mental processes caused by brain disease or trauma. Dementia classically presents with the triad of loss of memory, loss of skills and mood changes. There are associated behavioural changes along with:

- Apraxia (Inability to perform purposeful actions)
- Agnosia (Inability to interpret sensations)
- Aphasia (Inability to use and understand words and language)

In people with severe and profound learning disability it is often difficult to identify the above and dementia generally presents with behavioural and health-related changes.

There are a number of ways to try and establish whether a person with a learning disability is being affected by dementia. Steps that should be followed to arrive at a diagnosis include:

- Establishing baseline cognition and baseline health functioning.
- Establishing the presence of cognitive decline over a period of 6 months and any health-related or emotional decline, loss of language and self-care skills.
- Excluding health-related causes of decline (e.g. sensory impairment, coincident disease). Watching out for epileptic seizures or worsening of pre-existing epilepsy.
- Looking out for uncharacteristic behaviour and changes seen in dementia. Personality changes may also precede memory loss when dementia develops in Down's syndrome.

* Baseline Assessment

Mentaur Specialist Services recommends that from the age of 30 years all persons with Down's syndrome undergo a formal assessment. This should be repeated at regular intervals to enable early detection of dementia. We also recommend that this is also done for all persons with a learning disability after the age of 50 years.

Frequently people with a learning disability will present with symptoms suggestive of dementia but will not have had prior recorded assessments of their cognitive/general functioning. In the absence of formal baseline testing, it is imperative to gather as much relevant information about the person's normal functioning from carers, relatives and friends. Earlier recorded life story work is particularly helpful in this regard.

* Assessment Tools

Generic assessment tools used to diagnose dementia in the general population are inappropriate for use in people with a learning disability. However, many assessment instruments and tests have been developed specifically for this group.

These include general dementia screening tools, informal questionnaires, neuropsychological assessments, assessments of daily living and depression screening tools.

No single battery of tests to diagnose dementia in people with a learning disability is universally used in the United Kingdom. All assessments should include a direct assessment of the person and the application of a questionnaire to a close carer, relative or friend. The assessment should cover the person's cognitive and emotional functioning and assess for decline in functional capacity.

Where an assessment has already taken place, we recommend that the same assessment protocol be repeated.

With profound and multiple learning disabilities (PMLD) cognitive function is so poor that changes are undetectable on testing; carer reports take precedence here.

* Life Story Work

You must know the past of the person with dementia to know them.

Life story work can be the most important source of information, especially when the person's dementia is at an advanced stage. Life story books and memory boxes help build up a reservoir of knowledge about the individual.

Life story work also enables the understanding of certain individual behaviours, particularly behaviours viewed as challenging and serves as a tool in reminiscence therapy.

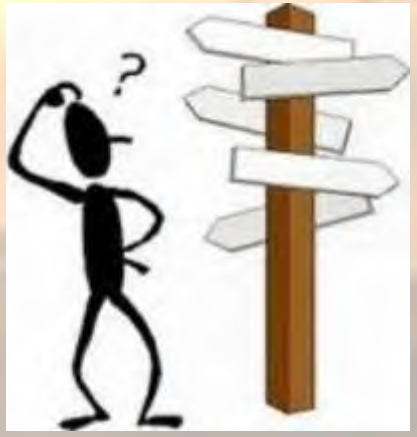
* Problems with Diagnosis

A lack of baseline information will often cloud the picture and compromise the diagnosis.

Inexperienced or untrained testers may not be able to accurately or correctly record the results.

Diagnosis may be delayed because carers have not picked up pertinent behavioural changes or may have increased prompting to overcome these changes. There may be an element of denial or reluctance to seek help.

Concurrent medical problems often serve to confuse the picture and delay and divert from the true diagnosis.



* Our Assessment Service

Mentaur Specialist Services, based at Aurora House, provides a full complement of trained and experienced staff to assess for the presence of dementia in people with a learning disability.

On referral, we will provide an initial assessment which will include gathering information on the person's previous and current functioning. We will also conduct at least a short test for dementia to allow us to reach a provisional diagnosis.

Depending on our findings, we may or may not ask to return to carry out more comprehensive testing. At all points during this process, we will be discussing our findings with the referring person or authority.

We have devised our own **testing protocol** with combinations of different tests and questionnaires for people with specific diagnoses and varying levels of ability. Our assessment team includes trained and experienced professionals from the fields of clinical psychology, psychiatry, nursing and social care.

Design Features

The design of Aurora House is geared to cope with the complexities of the relationship between the physical environment and the care that takes place within it. This involves a host of different factors.

* General Layout

The house provides a domestic environment along with a much higher than usual space per user ratio (over 55 sq m per service user).

There are seven single en-suite bedrooms catering for a variety of needs within the learning disability-dementia spectrum. Five of the bedrooms are suitable for people with locomotor difficulties of which three ground floor bedrooms are suitable for wheelchair users.

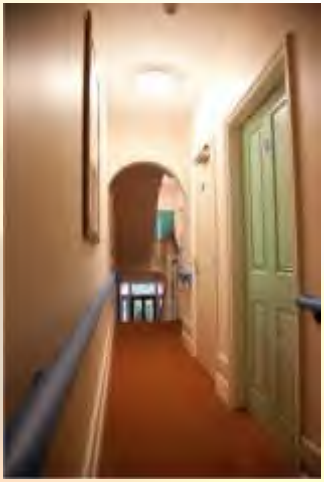
The home has a modern **lift** with inbuilt safety features suitable for people with dementia.

* Sensory Features

Colour- Colour is used to promote a calming effect and also for contrast. Soothing colours predominate along with sharp contrast colours on doors, floor-wall junctions, sanitary ware and hand rails to allow recognition and differentiation. Patterns and waves are avoided. Environmental labelling**,** through signage and colour**,** gives clues and prompts to support independent movement around the home. We expect the colour design to have a positive impact on the behaviour and mood of the users of service.

Illumination - Glare is avoided by using controlled lighting with dimmer switches. Sudden changes in light levels between and within rooms are avoided. Shadows may cause visual illusions. Where this is an issue direct sunlight is dispersed. Non-reflective surfaces are used.

Noise - The acoustics of the environment are improved by installing acoustic flooring, ceiling baffles, heavy wall hangings and other sound-absorbing materials**.**



Visual Access – The main living area has been opened up to allow users of service to look on to the outside world, including activities on the street. Wherever possible, they are able to view the WC in their en-suite bathroom directly from their bed. In general, there has been an attempt to allow people to see what they require from wherever they spend most of their time.

Flooring - Shiny, polished floor surfaces are avoided and designs kept simple. Colour contrasts are provided when users step out of a room into an adjacent area.

* Bathroom Design

Issues in focus include safety, the availability of adaptive supports, measures for water safety/control, easy movement and recognition of individual fittings. All bathrooms are en-suite and have walk-in showers. There are three disabled en-suite bathrooms**.**

Signage and Orientation – To maintain the domestic feel, we provide only necessary signage, placed in the most unobtrusive way. Orientation is through the use of familiar objects, good signage and colour.

* Furniture Design

In contrast to most dementia homes, the furniture has a distinctly modern feel and reflects the fact that people with a learning disability and dementia will tend to be younger and familiar with such objects. Sturdy, simple and versatile**,** the furniture offers a variety of seating choices and is generally free of sharp edges. Table tops/cloths are smooth and pattern free. Seating areas are provided in corridors.

* Activity Enhancing Elements

With an open plan kitchen, leading into an extensive living and dining area, we expect users of this service to engage in food preparation and be stimulated by the aromatic and visual contexts of food and cooking. The design allows them to safely maintain and develop food preparation skills up to their level of capability.

Scope for other activities includes easy and safe access to multiple indoor activity areas, laundry facilities and outside spaces including a shed.

There are small group and one to one sitting areas allowing for more personalised contact and in keeping with the general domesticity of the environment.

* Outside Spaces

There are safe and level outside spaces both at the front and rear of the property allowing for sitting out, walking and wheelchair transit through the entire ground level, both indoors and outdoors.

Steps have been converted into ramps where possible and required. It is easy to observe the activities of the street, the walking path is without clutter and safety features are unobtrusive. Plants and shrubs have been specially selected to stimulate the senses.

Aurora House Ground Floor Plan

Staffing

Senior staff at Aurora House have previous experience in both supporting people with a learning disability and people with dementia. We have a strong bias towards academics and research, having co-hosted a national conference on learning disability and dementia while lecturing and presenting widely on this area.

Staff Education & Training

A training needs analysis is undertaken for each member of staff and this training is consistent with their job profile and responsibilities. The service has a comprehensive and structured in-house education program for dementia in the context of a learning disability.

All members of staff are supported to pursue further education and relevant qualifications and are provided with educational materials to help support persons with a learning disability and dementia.

In addition to specialised training, staff undergo a full gamut of relevant training including issues relating to personalisation, life enhancement and choice.

Staff are also made aware of conferences and external training events relevant to their job responsibilities and interests.

The assessors in the service receive test and tool-specific training.

Keyworking becomes essential for this area of specialised need where memory is an issue and changes maybe subtle. We therefore try and ensure as much consistency as possible within the keyworking system.

Interdisciplinary teamwork, case discussion and regular reviews of need and the service are mandatory. **Families** are always invited to these reviews and meetings.

Information on ageing and dementia is offered to families and other interested parties and families are supported to gain understanding and knowledge of individual changes and needs.

Evaluation & Research

The progress of people living at Aurora House is the subject of continuous evaluation and all members of staff are informed and supported through this process. This also allows staff to gradually develop a reservoir of practical knowledge and expertise on issues surrounding learning disability and dementia.

Staff are encouraged to participate in all ongoing research projects in keeping with their job profile.

Lastly we encourage our staff to be flexible and compassionate with a sense of humour. We also recognise that they may need emotional support as the condition of the person they are supporting deteriorates or at end of life moments.

Care & Support

* Philosophy

Our philosophy embraces personalised support and care, safety, rights and choice while recognising, that for people with dementia, the focus must shift from enablement to preservation of existing skills.

We try and provide choice and control to our users with services that gravitate around their lives. We also work with the natural support provided by people's friends and family and with wider community resources.

* Communication

We emphasise that the quality of staff communication with people with dementia has a major impact on their quality of life.

A good knowledge of life history is therefore essential while developing and maintaining age-appropriate, person-centred communication.

We may use, as tools towards effective communication, passports, personal memory albums & charts, picture mats, familiar objects, pictures of reference, environmental signposting and signs and symbols. We may also use occupational, artistic and sensory stimulation to facilitate self expression. Recreational activities often open up new avenues for communication while reality orientation and validation therapy almost always facilitate communication.

Effective communication in dementia can be a challenge as the communication skills of the person diminish. We try and ensure the absence of unwanted noise and other stimuli and effective staff interaction to assist communication.

We facilitate staff training in this area and ask them to reflect on what they are expressing through their words and non-verbal cues.

* Health & Personal Care

People living at Aurora house have regular health checks and screening, following IASSID recommendations for dementia, and a health action plan. Staff are trained to manage medication safely and correctly.

We believe that medical treatment should be tailored to a clearly
established diagnosis and not to behavioural symptoms. NICE guidelines should steer the medical management of dementia.

Users of the service are encouraged to maintain a balanced and nutritious diet allowing for choice and individual preferences. Weight is monitored and towards the end of life, food and fluid intake monitoring may become necessary.

Personal and continence care is delivered by trained staff with supported choice and empowerment up to the level of the person's capability.

* Pain Management

Staff are trained in the early recognition, assessment and management of pain, particularly where a clear indication of the presence of pain becomes difficult to pick up.

Training is given on reversible and long-term medical conditions which lead to pain and users of service are assessed regularly for indicators of pain. Training is given on appropriate pain assessment tools and on behaviour that challenges, including the recognition that such behaviour may be caused by pain.

Wherever possible, we focus on the non-pharmacological management of pain including muscle relaxation training, exercise and specific equipment such as special cushions, mattresses and chairs.

Medical management of pain should be in line with NICE and WHO analgesia guidelines. We may also bring in specialist palliative care and expertise to advise on pain.

* Activities, Well Being and Social Relationships & Risk

People living at Aurora house participate in activities which are in concordance with their personality, choices, preferences and lifelong interests. We are of the view that in the early stages of dementia, new activities can also be introduced in a gradual and safe manner. All activities are reviewed and dynamically adapted across the continuum of dementia.

The design of the house allows for people to participate in activities in small groups in available private spaces or in a larger group when appropriate. Activities are adapted for sustainability to reflect the impact of increased impairment as dementia progresses.

Activities in the community and outdoor activities in the grounds of the house are keenly encouraged and help enhance social connectedness.

Users of the service are actively supported to maintain relationships with family, friends, peers and keep up previously established relationships.

Pursuing some of the above may involve a degree of **risk** and risk enabling strategies are discussed and agreed with the person and/or their circle of support. Risk enablement plans are based on awareness of the capacity for the level of risk to change over time and for different types of risk to emerge. They are reviewed regularly as dementia progresses or other factors come into play. The plans always take into account directions contained in the **Mental Capacity Act 2005 and the Deprivation of Liberty Safeguards (DoLS) 2008.**

* Available Therapies

Dance movement therapy is the psychotherapeutic use of movement and dance through which a person can engage creatively to further their emotional, cognitive, physical and social integration. It is founded on the principle that movement reflects an individual's patterns of thinking and feeling.

Art therapy follows the same principles through freedom of drawing and painting as a form of expression and promotion of psychological well being.

Music therapy uses music therapeutically to address the holistic and multidimensional functioning of persons with dementia. Music stimulates the senses and can bring about positive responses and changes in mood and behaviour.

Snoozelen environments increase the amount of sensory stimulation by provide changing visual stimulation, pleasant aromas, gentle music, and various materials of different textures to touch and feel.

All the above are accessible, fun and exciting forms of therapy available at Aurora House and offer an alternative to drug therapy. Sessions can be delivered on a group or individual basis and promote a holistic and personalised approach to the person's needs and desires. From singing along, to music of choice, to encouragement of free movement, to practising relaxation techniques, dance, art and music therapy offer an outlet for expression and the prospect of progress with mood, behaviour and social relationships.

There are other psychosocial interventions available at Aurora House which have research evidence to support their use in persons with dementia. **Reminiscence therapy** encourages reflection, reviewing key life events and bringing up linked emotions. **Validation therapy** helps resolve unfinished business in people's lives and relationships and is based on an attitude of respect and empathy, building a trusting relationship between the carer and the person with dementia. **Horticulture therapy** can both stimulate and calm and helps in the preservation of skills.

* Understanding behaviour

Staff are encouraged to try and view the world through the eyes of the person with dementia and understand their current reality. Any intervention therefore should address the person, the environment and the interaction between the two variables. Behaviour, therefore, is viewed as an attempt to communicate while making sense of an increasingly bewildering environment.

The person's life story is important in understanding behaviour. For example, the new or changed behaviour may be a return to previous behaviour and traits. The behaviour may be caused by a return to long term memory associated with that behaviour. Lastly, the changed behaviour maybe transitory to the stage of the person's dementia and may not need any intervention.

* Managing behaviour

Our service believes that proper analysis of behaviour, including the use of mapping tools, allows for good management. As a principle, we always try and promote positive behaviour and self esteem.

Sometimes simple environmental alterations or practical steps are the only interventions required. Other interventions may include new communication strategies, positive behaviour programming, counselling, medical evaluation and treatment.

Every attempt is made to rule out pain as a cause for the altered behaviour. We will also use anxiety management and relaxation techniques where indicated.

* Safety

Safety is ensured by a host of measures including robust risk assessment and care planning, staff training, personalised knowledge of users of the service including their capacity, by maintaining a safe environment and through technology.

* Use of Technology

The use of technology at Aurora House is adapted to the needs and capacities of it’s users and may include both 'high-end' and 'low-end' technology.

For instance, on the ‘high-end’ side, Aurora House uses a cutting-edge and person-centred call and assistive system. The nature of the technology allows risk to be significantly reduced while maximising freedom of movement around the premises. As a result, users of service with dementia move around without restriction and with the knowledge that, even when out of sight, staff are automatically alerted if they might require assistance.

In conjunction with relevant care and risk management plans, the system helps maintain a safe environment for it's users. Using a wireless environment, a simple web interface, and personalised risk profiles the system remotely supports the management of location, social and mobility related risks. Being simple to use, it enables staff to spend more time with those who need attention and less time on repetitive checking tasks.

At the other end of the technology spectrum, service users may use ‘low-end’ communication devices such as mats with attached pictures as an interactive resource to facilitate communication. These kinds of simple devices help people with communication difficulties to think about things discussed with them and pave a way for them to effectively

* Palliative care

In advanced and terminal dementia, a palliative care approach underpins management. Liaison with specialist palliative services is made where necessary. We ensure that staff are properly trained in the philosophy and principles of delivering good palliative care.

The psychological, emotional and spiritual needs of the person and also of the affected family are always respected. Palliative sedation therapy is only discussed as a last resort.

* End of life issues

We make every effort to provide a home for life at Aurora House for the person with dementia and to assist them to live in their home till their last days. Arrangements are made to support the person through this difficult period, and terminal care is given with dignity and comfort. At this difficult time, the person's spiritual and religious beliefs are always respected. Requests recorded in advance statements may be implemented at this time.

We try very hard to ensure the presence of people close to the person during the last moments of illness and life. Every opportunity is given to the person and to the family to grieve in these final days and again afterwards to the family. Staff are actively supported through a debriefing

Perhaps, just perhaps, it is not what paths we choose to take in life but, by some chance, who we choose to travel those paths with

~~*Diana deShaun and Lisa, Comes the Dawn*

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