MODEL OF CARE at Bloomfield Hospital for Huntington's Disease

Bloomfield
HOSPITAL

Contents

Introduction to Bloomfield Hospital

Founded by the Quakers in Ireland in 1812. Bloomfield Hospital is an independent, not for profit, 131 bedded facility located at the foothills of the Dublin mountains in Rathfarnham, Dublin 16. It commenced its service provision in 1812 and was originally located in Donnybrook until 2005 when it moved to its current location, which provides a state-of-the-art environment for the care and treatment of its patients and residents.

Foreword by the Chief Executive of Bloomfield Hospital

As we experience daily at Bloomfield Hospital, Huntington's disease is a rare and hereditary disorder of the brain which causes people to deteriorate physically, cognitively and mentally. It is a severe, progressive, genetic, and neuro-psychiatric condition. There is currently no cure for Huntington's disease. It can have a devastating impact on families – the distress of watching a family member deteriorate, the impacts of taking on caring responsibilities, and the worry of children and grandchildren inheriting the disease. It is estimated that there are approximately between 700 and 1,000 people in Ireland currently living with Huntington's disease, and more than 3,000 people living at risk.

Bloomfield Hospital is the only national service in Ireland providing inpatient care for Huntington's disease and we continually strengthen and develop our service based upon best evidence available and best international practice.

At the end of 2022, a planning and strategy group of Bloomfield Hospital staff across all disciplines visited Topaz Overduin Huntington's disease services in the Netherlands. On their return the energy, enthusiasm and commitment of the group was palpable. We set up several working groups to reimagine our Huntington's disease service and the work and output of the group and all our staff is phenomenal. We developed staff groups working on the Model of Care, equipment and facilities, partnerships and community, topaz interface, staff training & development, and Multidisciplinary Team (MDT) planning and care.

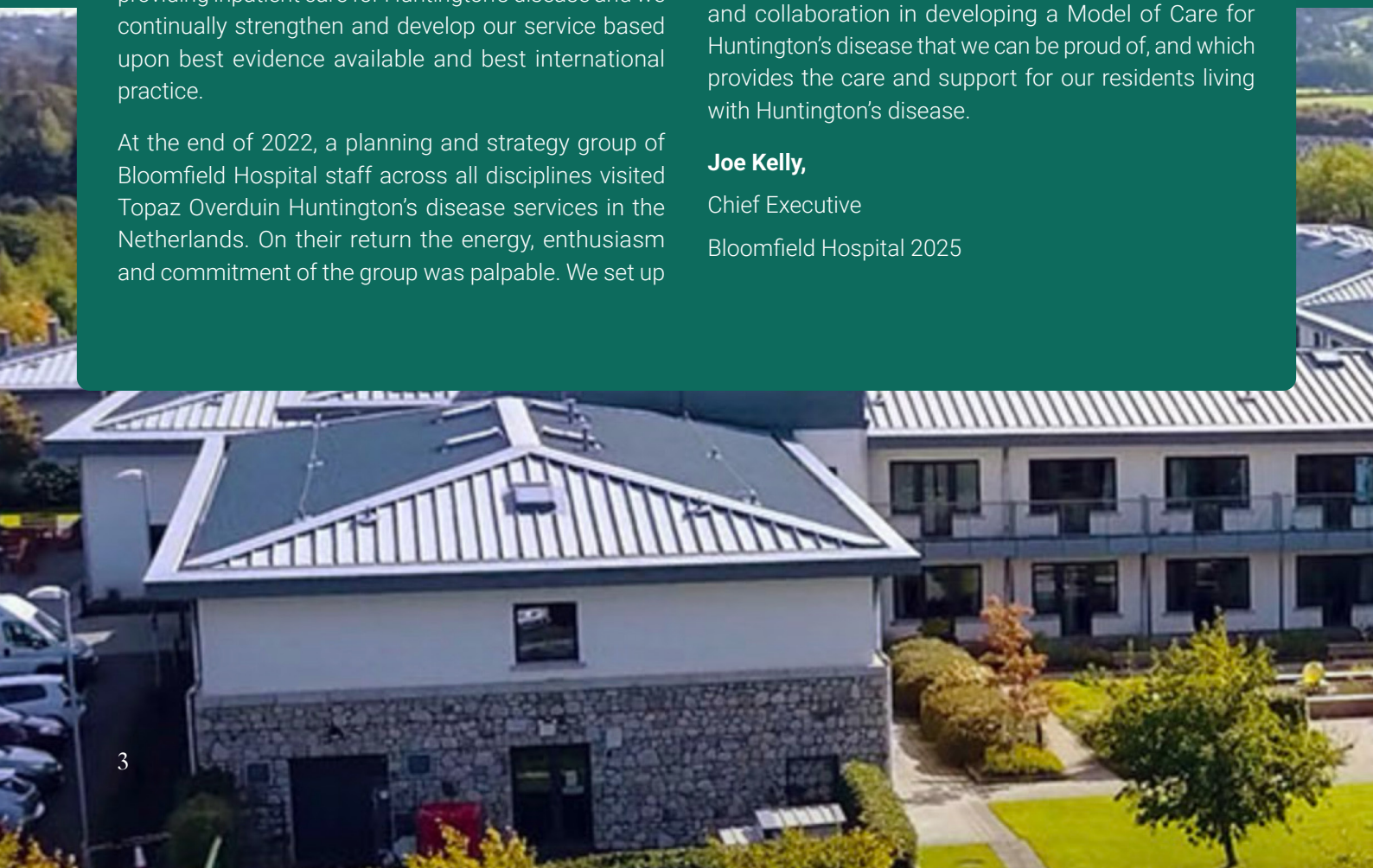
I am particularly pleased and commend our MDT and all of our staff for developing this Model of Care to continuously re-energise and reimagine our Huntington's disease service with the aim of establishing a Huntington's disease centre of excellence at Bloomfield Hospital.

I want to thank our staff for the great teamwork and collaboration in developing a Model of Care for Huntington's disease that we can be proud of, and which provides the care and support for our residents living with Huntington's disease.

Joe Kelly,

Chief Executive

Bloomfield Hospital 2025



Foreword by the Clinical Director of Bloomfield Hospital

As we continue to witness significant strides in our understanding and management of Huntington's disease it becomes increasingly clear that a comprehensive, patient-centred Model of Care is essential for improving the lives of individuals affected by this neurodegenerative disorder. Huntington's disease presents a unique set of challenges. Progressive motor, cognitive, and psychiatric symptoms require an integrated, multidisciplinary approach to ensure that patients receive the highest quality of care across the disease continuum.

The Model of Care outlined in this document reflects the growing recognition that Huntington's disease is not only a genetic disorder but also a complex condition that impacts all aspects of a person's life. From diagnosis to end-of-life care, each stage requires thoughtful, coordinated efforts that consider not just the medical but also the psychological, social, and practical needs of individuals and their families.

This model emphasises the importance of a team-based approach, where neurologists, psychiatrists, neuropsychologists, genetic counsellors, physiotherapists, occupational therapists, social workers, and other specialists collaborate closely to provide holistic care. It also underscores the significance of empowering patients and their families with the knowledge and resources they need to make informed decisions, navigate the complexities of the disease, and maintain the best possible quality of life.

Importantly, this framework supports not only clinical management but also the need for ongoing research and education. We are constantly learning more about Huntington's disease, and it is essential that our Model of Care remains flexible, responsive, and open to incorporating the latest advances in treatment and care strategies.

As Clinical Director, I am proud to advocate for a model that emphasises empathy, respect, and the inherent dignity of every individual affected by Huntington's disease. Together, we can ensure that people living with Huntington's disease receive the care and support they deserve, while also helping to pave the way for continued advancements in treatment.

Dr David Denton,

Clinical Director

Bloomfield Hospital 2025

Foreword by the Director of Nursing, Bloomfield Hospital

As the Director of Nursing, I am delighted to share this Model of Care with you. The team that developed this model have done so with passion, enthusiasm and expertise to create a greater understanding of the complexities of the disease and how it impacts the person, their family and support network.

This person-centred Model of Care optimises the delivery of care at all stages from the point of referral and admission through to the end stages of life and provision of palliative care.

The compassion and dignity that is afforded to each person is through this collaborative team approach which endeavours to ensure that each resident is part of our community and is empowered to be actively involved in their treatment and care.

Through continued education and developing research we increase our knowledge and understanding of Huntington's disease and share this with the wider clinical community which is essential for the first point of contact in shared services and creating shared care pathways.

It is my privilege to work with the clinical team here at Bloomfield Hospital in leading the way in supporting those with Huntington's disease.

Cathy Shelley,

Director of Nursing

Huntington's Disease Service

Huntington's disease is a progressive condition. This means it slowly gets worse over time. The way the condition progresses varies for each person:

Early stage:
symptoms are mild. You might feel moody or clumsy and struggle with complex thinking. You may also have small, uncontrollable movements, but typically, you can continue your everyday activities.

Moderate stage:
Physical and mental changes make working, driving and household chores very difficult. You may have trouble swallowing, which can make speaking and eating meals challenging but not impossible. Your balance may be off, increasing your risk of falling. You can still manage your personal care like bathing and getting dressed. You could perform better with a minimal support from somebody

Advanced stage:
Completing daily tasks is hard to do on your own. Most people can't get out of bed without help. You will need around-the-clock care during this stage, especially to eat, bathe and monitor your health and well-being.

The implementation process for the Model of Care will be underpinned by a detailed implementation plan and effective change management approach to ensure sustainability.

It will leverage synergies in areas such as screening, genetic counselling, support services, chronic disease management and research initiatives across all clinical service development and design

This also ensures the development of an effective integrated approach from multidisciplinary team to create an individualised care plan and follow up.

Background

According to the available information, there are over 700 people in Ireland now battling this disease - and some 400 who know they have the gene that causes it and will become ill at some time. A further 3000 are living with a genetic risk.

The progressive, neuro-psychiatric and hereditary nature of the disease brings a huge burden to families affected. Families of those affected warned it was a shocking indictment of Ireland that it is still without a specialist national clinic to help the most vulnerable people battling this rare disease.

The Huntington's disease care programme recognises the importance of involving people with the disease and their families in the design and delivery of Huntington's disease services.

The Huntington's disease programme promotes the development of Advanced Nurse Practitioners (ANP) and the advanced practice within health care profession and potential development of MDT resources in the holistic management of patients with Huntington's disease.

Aims and Objectives

Our aim is to create a Model of Care that is focused on our residents with Huntington's disease who also have a variety of psychiatric conditions.

The Model of Care for Huntington's disease services has been developed by the Huntington's disease Management Programme in Bloomfield Hospital. The aim of this Model of Care is to provide a framework for Huntington's disease services which follows international best practice and should be delivered within an integrated service approach. It covers the full spectrum of care provided in an inpatient setting. It also makes specific recommendations as to what type of care would be considered as best practice with respect to managing patients with Huntington's Disease in the community.

We strive to promote independence for our patients and residents as long as possible and to support them to live as full a life as possible, with the support and help of family, friends, and allied health professionals.

We deliver person centred, holistic, planned care that is delivered in a safe, appropriate, comfortable and homely setting.

We aim to be recognised centre of excellence using both national and international best practice.

We use validated outcome measures to assess and validate our work, placing a focus on our service users and their family's experience of service provision.

We are committed to ongoing training and education for our healthcare professionals to enhance treatment programs for the continued improvement of outcomes for patients and residents and the overall enhancement of their quality of life.

We also provide ongoing support and education for family members and caregivers through our family meetings and psychoeducation through our ongoing relationships and partnerships with third sector organisations.

Clinical Governance

Healthcare teams are accountable for the quality, safety and satisfaction of patients in the care they deliver. To enable us to continually improve our service and maintain high standards of care, we ensure that Clinical Governance is in place and applies measures to our work which include quality improvements, staff training, development and education. Clinical Audits, which ensures risk and compliance management, are strictly followed. Our Huntington's disease care team comes under Bloomfield Hospital governance structures with regular clinical governance meetings.

Clinical Governance

Quality Improvements	Staff Training	Development and Education	Clinical Audits

Referral & Pre-Admission Process

1. A completed referral form is received with accurate, up to date information on the patient, including a completed risk assessment.
2. The referral is pre-screened and an assessment is arranged with the referring team.
3. If further information is required, the service will be contacted immediately with a request to provide it.
4. A specialist clinician and a senior member of the nursing team will assess the patient. In some cases, other members of the multidisciplinary team will contribute to the assessment process as appropriate. Assessments take place following receipt of the completed referral form and relevant information.
5. Following the assessment, a decision to admit will be made at an admissions meeting and an appropriate bed will be assigned to the patient.
6. Admission to the service is conditional on approval of funding from the referral source.
7. Please see our website for the most up to date information on referrals and admission available at www.bloomfield.ie

Comprehensive Assessment

We provide the following assessments during a residents stay including:

Holistic Evaluation
A thorough assessment of mental, physical, cognitive, and social factors is conducted for each patient to determine the impact of Huntington's disease

Cognitive Testing
Neuropsychological assessments to identify cognitive impairments.

Functional Assessment:
Evaluation of the patient's ability to perform activities of daily living (ADLs), which can affect their overall well-being.

Falls Risk Assessment Tool (FRAT):
The Peninsula Health Prevention Service developed the FRAT. The FRAT is completed by nursing staff in hospital and discussed at MDT. It is useful in providing a focal point for all falls related information. It helps in predicting the fall risks of individuals with accuracy. It is useful for identifying people who are most likely at high risk and aims to direct resources towards them. The FRAT can target preventive measures for those identified at medium or high risk of falling.

Modified Barthel Score:
The Barthel index is the most widely used measure of activities of daily living (ADLS). Ten basic activities of daily living (ADLs). It measures the likelihood of being able to live at home with a degree of independence. Ten basic activities of daily living are captured: bowels, bladder, grooming, toilet use, feeding, transfers, walking, dressing, climbing stairs, and bathing.

St Andrew's Healthcare Nutrition Screening Instrument (SANSI) for Huntington's disease:
The SANSI tool is a four-step screening tool which captures the risks including dysphagia, the need for tube feeding, special dietary requirements, selective eating, food/fluid refusal and obesity.

Multidisciplinary Team Care

Nursing Assessments:

a) Activities of Daily Living (ADLs)

This is to assess a patient's functional status. They are the basic task, which must be accomplished every day for an individual to thrive. They are broken down into categories.

- **Maintaining a safe environment**
  We provide support for residents to be orientated to the ward, their bedroom is clearly signposted, appropriate lighting is provided, toilets signposted etc.

- **Communication**
  We assess the resident's ability to use language, use a telephone, send and receive letters and aid in helping them to communicate unmet needs. We often manage residents with expressive and receptive dysphasia.

- **Breathing**
  Common cardio-respiratory conditions such as lung cancer, chronic non-malignant lung disease, and heart failure increase in prevalence with age and are common causes of breathlessness (60% - 88% with heart failure and 90% - 95% late-stage pulmonary disease). Some of our residents require supplemental oxygen.

- **Eating and drinking**
  We assess residents' ability to prepare a meal, check that they are able to feed themselves, make choices of menu, and assess whether they require a special diet due to risk of aspiration or require nutritional supplements.

- **Washing and dressing**
  A regular shower, grooming, oral hygiene and nail care routine is important. We maintain privacy and dignity and assess the way that residents like things done.

- **Physical observations**
  We monitor physical observations routinely. Changes in temperature, blood pressure/pulse/respiratory rate could indicate sepsis. Infection can increase the risk of delirium.

- **Toileting**
  We monitor for any urinary or faecal incontinence. Bowel movements are closely observed as constipation can be a risk factor for delirium.

- **Mobility**
  We assess a resident's ability to weight bear and move from one position to another. We assess their ability to transfer from a bed to chair or to a wheelchair. We explore whether they need a walker or other assistive aids or can walk independently.

- **Working and playing**

We assess the resident's ability to engage in activities.

- **Expressing sexuality**
- **Sleeping**
- **Palliative care**

This assessment is used in conjunction with five additional determining factors:

- **Biological**
This considers the patient's current and past history, strengths and vulnerabilities.

- **Psychological**
This considers the individuals core beliefs and cognitive functions, and how these effect the individual's ability to execute activities of daily living independently.

- **Sociocultural**
We consider the person's history and cultural beliefs, and the beliefs of those around them. This can affect recovery and the ability to function independently.

- **Environmental**
The factors consider how the environment impacts healing and wellness.

- **Financial**
We assess the resident's ability to access personal funds, public and private programmes and insurance to accomplish health and wellness.

A combination of both assessment tools forms the foundation of a care strategy for the patient and helps to empower individuals when discussing care goals with the MDT.

Difficulties with ADLs often correspond to how much help, supervision and hands-on care a patient needs. For each ADL, residents can vary from needing just a little help, such as reminders, to full dependency. This may require partial or full assistance with tasks.

b) Abbey Pain Scale

This is a standardised pain assessment tool developed for use in dementia and non-verbal patients. Pain assessment is difficult in non-verbal patients. Changes in facial expression, grimacing, behavioural changes such as restlessness, agitation, vocalisation and an increased heart rate can indicate pain.

c) Skin Integrity Assessment

The patient is fully examined for skin abnormalities. It requires visual inspection of the skin from head to toe with particular emphasis on body prominences and skin folds.

d) Waterlow Assessment

The Waterlow score estimates the risk of developing pressure sores.

e) Barthel Assessment

This measures the performance of Activities of Daily Living. Each performance item is rated on a scale given a number of points assigned to each level of ranking. This can identify the dependency level of the patient.

f) FRAT Assessment

This is a risk assessment tool for falls. It helps to identify the risks of falling and is a quick and easy tool to assess an individual's falls risk. This can be used for all individuals you think may be at risk of falling and giving guidance on specific areas surrounding the individuals falls risk.

g) MUST Assessment

This five step screening tool to identify adults who are malnourished, at risk of malnourishment or at risk of obesity. It includes management guidelines, which can be used to develop a care plan.

h) Social Functioning Scale

Measures social skills and performance to cover functions that are important for patients suffering from schizophrenia. It assesses the presence or absence of key skills and social behaviours in the person.

Medical Assessments

a) Medical/Psychiatrist Assessment on Admission.
A full physical examination is conducted by a general practitioner, medical officer or Consultant upon admission. This includes an assessment of the resident's history and collateral information, blook tests and other investigations, imaging, cognitive or neuropsychological testing as required.

MDT members are consulted to discuss the assessment of the patient and to reach a consensus agreement regarding the person's diagnosis in individual care plans.

The physician then collaborates with MDT colleagues to provide a person-centred care plan, ensuring:

- Involvement of relevant people and agencies
- Forward thinking and anticipation of changing needs
- The use of effective interventions tailored to the individual
- The quality of life for the individual is upheld and improved upon
- Regular reviews of the plan and activities
- Support to caregivers, families and friends

A team-based approach is essential for managing elderly psychiatric patients due to their complex needs.

- **Role of the Neuropsychiatrist**
  The neuropsychiatrist is directly involved in addressing the emotional, cognitive, and behavioural components of the disease, with the aim of improving quality of life for both patients and families, ensuring comprehensive care throughout the progression of Huntington's disease.

  Since the psychiatric symptoms of Huntington's disease can overlap with other mental health conditions, neuropsychiatrists help differentiate Huntington's disease from other neurodegenerative or psychiatric disorders.

- **Dietician**
  Through ongoing assessments, nutritional management and collaborative care, dietitians are essential in supporting Huntington's disease patients to maintain health and quality of life across all disease stages.

- **Speech & Language Therapist (SLT)**
  The SLT also plays a key role in working to support and educate the MDT to maximise their communication interactions with the patient and their ability for oral intake and implement swallowing care plans and future feeding plans.

- **Social Workers**
  Address social determinants of health, help navigate care systems and provide support for family caregivers.

- **Occupational Therapists**
  Help improve functional independence and quality of life.

- **Neuropsychologist and Therapists**
  Neuropsychologist and Therapists offer a programme of psychotherapies tailored to HD patients, such as cognitive behavioural therapy (CBT), cognitive stimulation or xx therapy.

- **Physiotherapist**
  Physiotherapy plays an important role in the multidisciplinary management of Huntington's disease, aiming to improve the patient's quality of life, maintain mobility, and delay functional decline.

Nursing Team

Our Huntington's Disease nursing team comprises of:

- Director of Nursing
- Assistant Director of Nursing
- Clinical Nurse Managers 1, 2 & 3
- Registered Nurses
- Health Care Assistants and Activity Co-Ordinators

Specialist nurses in Huntington's Disease ensure consistent, high quality care is given to our residents and that meaningful goals are developed collaboratively with the resident and family members

Our nursing expertise has been established through the experience of working with Huntington's Disease over the past 10 years. Through our experience and knowledge, we have developed a bespoke approach to caring for residents who have Huntington's Disease. This includes significant training and development of our staff in understanding and caring for residents with Huntington's Disease. Part of this training has been developed by key MDT members such as SALT. Other aspects of our specialised training programme have been developed (and approved by the Nursing and Midwifery Board Ireland) by our CNM3.

Our Clinical Nurse Managers hold a pivotal role in providing on the ground leadership, support and guidance to the nursing team to ensure the highest standard of care is provided to our residents with Huntington's Disease. This includes awareness of the associated risks for residents living with Huntington's Disease, while promoting quality of living and independence for as long as possible.

The nursing team in Huntington's Disease ensure specialised quality care is given to our residents and that meaningful goals are developed collaboratively with the resident and family members. These goals are varied and are documented in the Individualised Care Plan. They include goals such as: essential care needs, positive risk management, therapeutic activities, social engagements, therapeutic leave, emotional supports, family supports etc.

Residents with Huntington's Disease are supported by our nursing staff when difficult decisions that need to be made are being discussed and considered. For instance, in the event that a resident is deciding whether to opt for peg feeding. Our nursing staff act as advocates for our residents and ensure where necessary Decision Support Services are available. The nursing team, in collaboration with the resident and the MDT: assess, plan and implement evidence-based care that has specific focus on the symptoms of Huntington's Disease and ultimately evaluate the efficacy of the treatment plans.

Our Health Care Assistants work under the close guidance and support of our registered nurses. They provide daily care for our residents across all presentations and stages of Huntington's Disease. Our activity team facilitate a wide range of activities for our residents both on and off the unit. The activities offered cover all ranges of abilities to ensure meaningful engagement for our residents.

Integrated Mental and Physical Health Care

Many of our patients have physical, psychological and emotional concerns secondary to Huntington's disease making it necessary to integrate physical and psychiatric care. Addressing medication management is critical to avoid drug interactions and side effects, especially considering polypharmacy.

Psychosocial Interventions

Neuropsychology
Cognitive-behavioural therapy (CBT), interpersonal therapy, and other psychotherapies can be effective in treating depression, anxiety, or irritability in Huntington's disease patients.

Family and caregiver support
Family members often play a significant role in caring for Huntington's disease patients and involving them in the care plan is essential. They may benefit from psychoeducation about the condition or medication.

Pet Therapy
Irish Therapy Dogs is a registered voluntary charity whose approved volunteers and their dogs visit the residents of an assigned Care Centre once per week for approximately one hour to bring them the therapeutic benefits of canine companionship.

We have a dedicated activity centre with daily activities and entertainment providing a rich array of social activities. We provide residents with a timetable and offer a programme of various activities which cater for all tastes and allow for an element of choice.

Environment

Bloomfield Hospital provides specialised long-term care for those affected with Huntington's disease.

This helps us to fully assess and understand a patient unmet needs over a period so that they get the most appropriate holistic care.

All residents in Bloomfield Hospital benefit from high quality living environments which include: a sitting/living room, dining area and kitchen within the mixed gender unit.

Accommodation in Bloomfield Hospital benefit from high quality living environments which include: a sitting room/living room/dining area and kitchen within the mixed gender unit. Accommodations are in a range of four bedded units, two bedded units, the majority of the bedrooms are single en-suite. There are assisted bathrooms located on each corridor and all the residents have access to outdoor space.

- Other facilities provided include:
- Physiotherapy Gym
- Therapeutic Kitchen
- Art Therapy/Men's Shed Room
- Multi Faith Room
- Hair/Beauty Salon
- Family Room
- Shop
- Reminiscence Corner, Street Scape, Poetry Corner and Art Displays
- Restaurant facilities where patients can eat off the unit
- Sensory Garden
- Day Centre with in-house activities for all residents
- Horticulture

Person-Centred Care

This approach tailor's interventions to the individual's preferences, values, and needs. It includes:

- **Respect for autonomy**
  Encouraging patients to be active participants in their care decisions.
- **Cultural and spiritual sensitivity**
  Acknowledging the role of cultural, religious, or personal values in shaping care.

Management of Behavioural and Psychological Symptoms

We provide management of agitation, aggression and other behavioural symptoms are managed with pharmacological and non-pharmacological interventions.

Non-pharmacological interventions are prioritised, including environmental modifications, structured activities, and behavioural therapies. Individual behaviour management plans are found beneficial in management of patients with Huntington's disease.

Medication Management

Bloomfield Hospital provides a regularly monitored pharmacological management:

- Frequent reviews of medication regimens to minimise polypharmacy and adverse effects in line with MHC guidance.
- Use of antidepressants, antipsychotics, or mood stabilisers cautiously, with consideration for physiological changes in Huntington's disease
- We review and audit medication strategies via our Drugs and Therapeutic Committee considering the most up to date clinical research and evidence as well as regulatory considerations

End of Life & Palliative Care

Huntington's disease patients may require palliative care to manage chronic pain, distressing symptoms, and provide emotional support at later stages of the disease/end of life.

Advanced care planning: Engaging the patient and family in discussions about treatment preferences, including use of cardiopulmonary resuscitation (CPR) and power of attorney.

We have progressive Advanced Health Directive documentation which helps to provide a comprehensive plan as part of a patient's wishes.

Prevention and Early Intervention

As part of ongoing MDT processes, we provide mental health screening for a variety of comorbid disorders such as depress or cognitive decline.

Caregiver Support and Education

Education and training for family caregivers are vital in managing the complexities of psychiatric care.

This model recognises the intricate interplay of mental, physical and social challenges in patients, offering a comprehensive, coordinated, and person-centred approach.

Legal Support

We provide support within existing legislation for residents.

We obtain high quality legal advice from the Mental Health Act office, legal counsel and the Decision Support Service for the following areas:

- Mental Health Act 2001
- Assisted Decision Making (Capacity) Act 2015
- Decision Making Representatives
- Advanced Health Directives
- Enduring Power of Attorney
- Inherent Jurisdiction

Quality and Compliance

Bloomfield is proud to provide high quality care to our residents as a national and regional centre of excellence for neuropsychiatry and specialist rehabilitation.

Bloomfield typical aligns its policies and procedures with the HSE and other providers. This includes following consensus best practice guidance for the care of our patients.

We follow the MHC Quality Framework for Mental Health Services in Ireland which provides a mechanism for services to continuously improve the quality of mental health services. It promotes an empowering approach to service delivery, where services facilitate an individual's personal journey towards recovery.

We continue to collaborate with academic leaders within Trinity College Dublin and University College Dublin where it comes to research and education to help improve services and to keep up with changes in the delivery of high-quality mental health services.

We also develop our programmes through co-production and consultation with advocacy groups such as the Huntington's Disease Association of Ireland who give us regular feedback.

Notably, Bloomfield have consistently received high compliance scores from the Mental Health Commission when they inspect our premises and services.

Our team of experienced clinicians attend regional, national and international conferences networking widely to help keep up to date in advances in neuropsychiatry and the management of severe and enduring mental health issues to help make sure we get the best outcomes for our residents.

We also receive training from the Mater Lean Academy to learn how to improve and make lasting change with tangible outcomes in healthcare through their practical and accredited Lean Six Sigma in Healthcare Programmes. Clinicians learn how to improve and make lasting change with tangible outcomes. This supports us with our ongoing quality improvement programmes, audits and service evaluations where we routinely measure the quality of care provided.

bloomfield.ie

Bloomfield Hospital
Stocking Lane, Rathfarnham,
Dublin 16 D16 C6T4

Tel: (01) 495 0021
Email: info@bloomfield.ie

bloomfield.ie