



**Brightwater**  
We see what others don't



## Brightwater Service Deliver Model for **People with Huntington's Disease**

## **Purpose**

The purpose of this service model is to describe the care requirements of people with Huntington's Disease, including current practices and new approaches for implementation of Supported Independent Living services for people with Huntington's Disease in the context of Specialist Disability Accommodation (SDA) houses at Piara Waters that are also managed by Brightwater.

## **Foundation Principles**

1. The built environment must meet the needs of people with Huntington's Disease, which includes physical, neurological, social and emotional features of the neurodegenerative presentation, as well as consideration of the multigenerational, familial nature of the disorder.
2. Our comprehensive set of services for people with Huntington's disease supports:
  - a. connectedness of the Huntington's community with Brightwater from the earliest stages of disease;
  - b. all activities of daily living including engagement and relationships with family, social connections, and other service providers; and
  - c. personal choice, empowers decision making across the disease progression, encouraging each person to retain the skills required to achieve optimal quality of life and independence for as long as possible.

## **Philosophy of care**

Our philosophy is that we enable people to live their lives as independently as possible for as long as possible despite the confines of the disease, bring certainty to their lives, and support family engagement.

Our approach is customised and driven by the pace determined and dictated by the client. We recognise the importance of engaging with clients to recall and celebrate what they have done in their lives and the meaning it has for them.

The model of service is consistent with Brightwater's Mission: Pursuing the dignity of independence.

- Brightwater values the potential of each of its clients supporting them to actively participate in both their immediate living environment and local community according to individual choice
- Brightwater offers its clients the dignity of control over their own lives
- Brightwater works in partnership with clients and families

## **Informed Innovation**

Brightwater has designed new SDA homes for people with Huntington's Disease which:

Reflect the care requirements of people with Huntington's Disease;

Assist staff in providing optimal care outcomes for clients;

Demonstrate learnings in design from 30 years of specialist accommodation provision;

Is informed by innovations from national and international agencies;

Is developed through co-design with people with Huntington's Disease, their representatives, and a range of stakeholders in the Huntington's community; and

Provides opportunity to both effectively and efficiently staff the service within the confines of a National Disability Insurance Scheme (NDIS) funding model and in compliance with NDIS Quality and Safeguards Practice Standards.

## **Service Delivery Expertise**

Brightwater has provided specialist accommodation and daily personal care supports for people with Huntington's Disease since 1993.

Huntington's Disease is an incurable, life-limiting, primarily adult-onset hereditary neurodegenerative disease. It is characterised by a triad of neurological symptoms, notably cognitive decline, motor abnormalities, and psychological change. The disease results in the gradual loss of ability to carry out everyday tasks, with individuals becoming increasingly dependent on others over its course. Current literature indicates that life expectancy is approximately 15 to 20 years following the onset of symptoms, however, this may vary depending on other factors including age of onset and lifestyle.

The age of onset is highly variable, with most people becoming symptomatic during mid to late middle age. As such, it presents during the significant life stage where many people are involved in career development, child rearing and financial consolidation. Whilst the age of onset and rate of progression of Huntington's Disease are traditionally recognised as being influenced by genetic factors, it is now widely acknowledged that environmental factors can also be important. As such, the importance of supporting individuals with Huntington's Disease to remain physically and cognitively active cannot be underestimated.

Huntington's Disease is a family condition. As an autosomal dominant disease, any child of a parent with Huntington's Disease has a 50% chance of inheriting the condition. The inter- and intra-generational impacts of the disease are profound with devastating impact on families across multiple generations.

The document, Living Well with Huntington's Disease: Community of Practice Framework (2017), which Brightwater co-developed in collaboration with other leaders in the field, provides evidence-based principles of care that strongly endorse the protection, empowerment, and support necessary to optimise the health, wellbeing, and quality of life of people living with Huntington's Disease. The Practice Framework principles of care advise that care should: be holistic, personalised and family centred; include a lifespan approach; support wellness and enablement; provide supported decision making; and offer flexibility, predictability, hope and resilience, legacy, and support for carers.

Brightwater is a cofounder of the Supported Independent Living for People with Neurological Disability Community of Practice (CoP) with Yooralla, the only other organisation in Australia providing dedicated 24/7 care for people with Huntington's Disease. Through this CoP, Brightwater and Yooralla are collaborating to provide a place where like-minded organisations can come together to share ideas, policy documents, brainstorm issues and create a stronger voice for people with a neurological disability living in supported independent living.

People with Huntington's Disease are eligible for participation in the NDIS and, as an individual's functional capacity and psychiatric presentations evolve with disease progression, they become eligible for different categories and levels of funding that may include support coordination, capacity building supports (allied health), supported independent living (SIL), positive behaviour support, specialist disability accommodation (SDA), and some limited health related services and consumable products. Brightwater has significant experience transitioning individuals onto the NDIS and evolving the service model to roster staff effectively and efficiently within the confines of a NDIS funding model

and in compliance with NDIS Quality and Safeguards Practice Standards, and to increase engagement with the range of other service providers supporting various elements of each individual's care plan.

## **Built Environment**

Brightwater's SIL and Capacity Building teams informed the SDA build design to meet the needs of people with Huntington's Disease, including consideration of physical, neurological, social and emotional features of the neurodegenerative presentation, as well as the multigenerational, familial nature of the disorder.

## **Co-Design Outcomes**

The familial nature of Huntington's Disease, and shortened lifespan, means that opportunity to share meaningful time with family is of upmost importance. Outcomes from co-design workshops, including client representatives, families, carers, allied health, and external clinical specialists, revealed the overwhelming preference of stakeholders that the built environment include private and shared social spaces, natural light, significant access to nature, inspiration for mobility, and well-placed shade protection to enable social interactions outdoors throughout the year, rain or shine. The environment should be as home like as possible, welcoming for families with children, and nurturing for gene positive relatives who will require Huntington's Disease specific supports in the future. Participatory outcomes are key drivers of co-design and linked to the measure of success.

## **Location**

The land in Piara Waters was selected for its geographic proximity to the growing population on the southern outskirts of the Perth metropolitan region with access to basic health, recreation, NDIS Community supports, and other commercial resources, as well as a tertiary hospital. The campus is in a suburb with affordable housing, schools, and availability of childcare options to maximise opportunities for support staff to live and work in the local community. The campus is close to, but set back from, arterial roadways, and is adjacent to a small shopping centre which further nurtures integration of residents into local community life and creates opportunity for individuals to maintain independence for as long as possible.

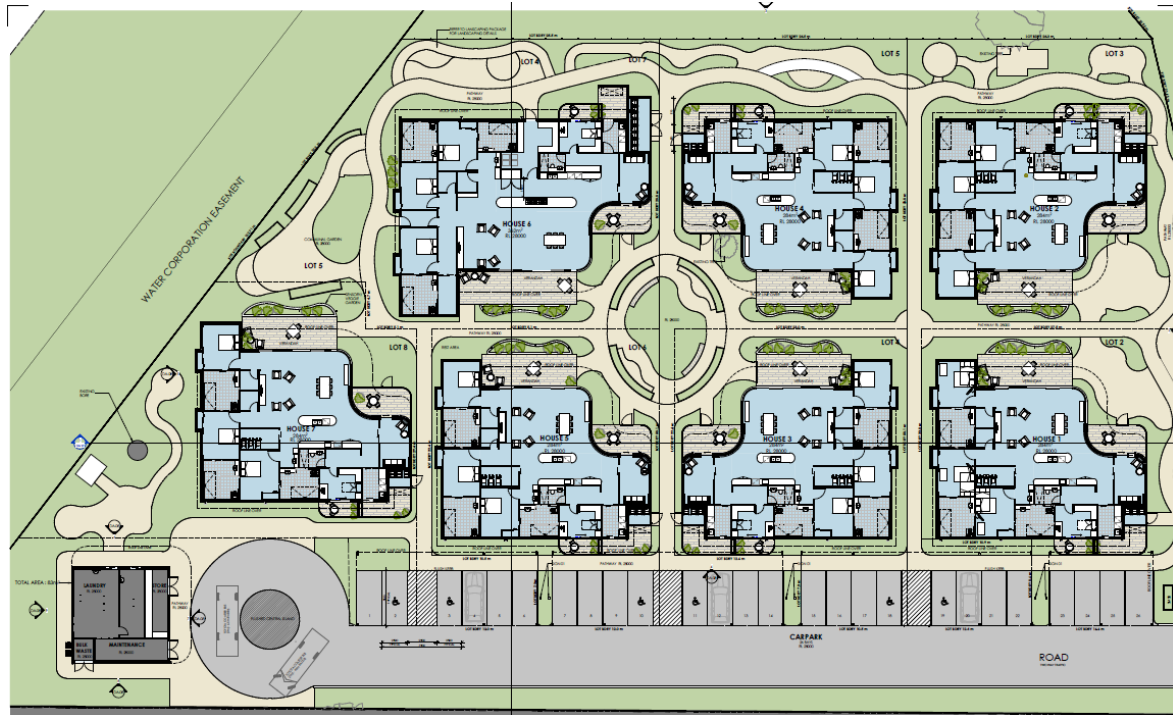
## **Build Design Features**

The Brightwater community of SDA houses at Piara Waters includes 7 x 3-bedroom strata homes built to National Disability Insurance Agency SDA design and regulatory standards (Figure 1). The build design includes substantial natural light and provides both private and shared communal spaces for up to 3 people per house. Each resident has their own bedroom and large ensuite. The integration of open plan indoor and outdoor spaces combined with semi-private patios and living rooms enables residents to move freely while having confidence that support staff have line of sight through and between most of the properties. This design was achieved through evidence-based learning as part of delivering care for people with Huntington's Disease over many years, and confirmed through co-design engagement with participant representatives, specialist clinical teams, and other stakeholders.

Two houses face the street to maximise community participation while residents are able and choose to access local amenities more independently. Four houses face into a spacious shared courtyard that encourages continued social engagement, physical movement, and connection to nature. One house provides increased level of privacy at the back the property, which is a preference for some individuals.

The Campus includes a dedicated building for receipt of large deliveries, such as groceries and continence support products for distribution to each house, and heavy-duty laundry to process large items like soiled linens away from the daily activities of each house.

**Figure 1. Layout of Brightwater community of SDA houses in Piara Waters**



In addition to the private bedrooms and ensuites for residents, each house is equipped with an accessible domestic kitchen, inviting use by clients, staff and families, and accessible laundry to maximise independent routines and continued participation in activities of daily living. Each house also includes dedicated storage to accommodate large chairs and other equipment typically required for people with Huntington's Disease, built in tracks to enable installation of ceiling hoists, and an overnight assistance room for staff and overnight visitors. One house has a larger kitchen with butler's pantry for preparation of modified texture foods to be delivered across the campus as needed, and an extra-long counter for increased opportunities for engagement in the sights, sounds and aromas of the meal preparation experience.

**Figure 2. Individual house design**



## **Garden Spaces/Outdoor Areas**

Landscaping design plays a significant role in quality of life. The exterior environment is inviting for clients, families, and children to nurture social engagement, family connection, and contact with nature. It is constructed to maximise accessibility and enjoyment for people with different levels of mobility and provides therapeutic features co-designed with allied health specialists, to maintain strength and support continued movement.

The houses are all connected by a large sensory garden space with different “rooms” to support a variety of outdoor experiences for the clients and to encourage families, staff, visitors and volunteers to spend time using the spaces both for their own enjoyment but also as part of an opportunity to interact with the clients. The garden “rooms” will include spaces for sitting in quiet contemplation, spaces for active involvement, such as the kitchen garden and spaces that create mobility challenges for both clients and potentially any visiting children.

The social nature of the gardens is essential in encouraging both together time and alone time in a client population who are often significantly challenged in their ability to form and maintain social connection. The added value of using other senses such as smell and taste as well as in encouraging mobilisation all address issues of change caused by the disease whilst supporting staff and significant others to join with the clients in these spaces and activities. Brightwater envisages the small undercover courtyard at the front of each house being a private space for resident alone time and time with families.

Use of the gardens will be guided by the clients who will be encouraged to independently access the spaces or offered access support as their mobility declines. Evaluation of weather conditions will be important and staff will offer guidance to clients to ensure sun and rain protection is utilised as required.

## **Model of Care: Support for People with Huntington's Disease**

### **Objectives**

Provide SIL in a housing environment that can adapt to significant changes in client physical, social, emotional, and clinical requirements ranging from semi-independent to fully dependent and palliative care.

1. Use an active support approach empowering clients in skills around self-management to enable improved wellbeing. Reduce the impact of the degenerative process through engagement with a stimulating and structured environment.
2. Develop an individualised program for each client based on their goals and objectives for supported community integration, maintaining wellbeing, social connections, and quality of life.
3. Ensure that each client retains, for as long as possible, the skills required to achieve optimal quality of life and independence.
4. Support clients and their families to maintain social connections, empower decision making and preparation for end-of-life care, and support exploration of alternative accommodation options as and when appropriate.

### **Support through disease progression**

People in the earlier stages of Huntington's Disease present with deficits in the ability to manage key areas of their lives including hygiene, diet, finances, and social relationships. Support for this skill development and maintenance may also be provided by Brightwater in the community. The Brightwater model of care includes engagement with individuals, their families, and other representatives in the community aiming to support people to live at home for as long as possible.

As the disease progresses, presentation becomes more physically based with decline in mobility, swallowing, and capacity to self-care. Care needs may require the individual to consider residential accommodations. It is recognised that people with Huntington's Disease benefit from a small home setting that is focused on maintaining and re-establishing functional independence. This setting is provided within Piara Waters. An integral part of the SIL service is proactive engagement with individuals, their families, and other representatives to encourage conversations about advanced health care planning and end of life decision making to maximise representation of the preferences of the individual. This decision making may include consideration of movement to different houses where there is capacity to do so, and it is agreed by all stakeholders that such a move would provide appropriate care and support for the individual. Brightwater is committed to supporting individuals throughout the disease progression inclusive of the palliation and end of life process.

### **Historical context:**

Kailis House opened in 2009 and moved to a purpose-built duplex in Belmont in 2011 to support clients in earlier stages of Huntington's Disease progression. Clients in Kailis were required to have physical independence in basic self-care and mobility at a minimum. Some demonstrate a moderate degree of independence in community access. Ellison House has provided accommodation and support for people in the later stages of Huntington's Disease including full physical care, behavioural management, and access to palliative care. Clients would move from Kailis House to Ellison House when their care needs increase beyond prompting or minimal physical assistance. Clients could also

choose to move to an alternative care environment and were supported to plan for preferred future accommodation whilst living at Kailis House.

### **Contemporary model:**

The 3-bedroom SDA houses co-located in community environment provide increased choice and control for residents and capacity for agility as a service provider. SIL clients are offered the opportunity to age in place or relocate within the campus to maximise access to appropriate staff ratios and clinical support, while maintaining meaningful relationships with other clients. Residents who share an SDA house have the right to choose their SIL provider and there may be circumstances where an external provider is engaged for a particular house.

### **Community Support prior to SIL Admission**

- Brightwater delivers capacity building and therapy services for individuals with Huntington's Disease in the community to support individuals to live independently for as long as possible. Where individuals choose Brightwater community-based services, they can develop relationships with our service model prior to admission to Brightwater SIL.
- Brightwater works closely in collaboration and communication with sector stakeholders including, but not limited to, the Department of Health WA, WA Neurosciences Unit (NSU), the NDIS, Huntington's Australia, Huntington's Disease Network of Australia national Huntington's Disease register, Neurological Council, internal and external support coordinators, and others.
- The Brightwater Capacity Building Program's team approach to individual services for people living in the community with Huntington's Disease includes traditional therapy disciplines, support coordination, behaviour support and registered nursing consultancies.
- Clients may choose to access SIL services at various stages of the disease progression.

### **Referrals and Admissions**

#### **Who is eligible for the service?**

Clients accessing services through the Capacity Building Team will required to be able to fund therapy, behaviour support and support coordination services either utilising funding available in an NDIS plan or on a fee for service arrangement.

All clients receiving Brightwater SIL Services need to be eligible for the NDIS or other relevant source of funding for care. Residents applying to live in an SDA house must be eligible to access SDA funding in their NDIS plans.

SIL clients must have a funding plan including SIL or sufficient core funding for assistance with daily personal tasks (including SIL). It is desirable that SIL clients with Huntington's Disease have capacity building, consumable products, and health related support funding in line with their functional capacity and needs.

#### **Admission process**

The Brightwater Welcome Team is the first point of contact for all initial enquiries to Brightwater Disability services including SIL, SDA, and Capacity Building. The process detailed below assumes that



Brightwater is the client's preferred SIL provider. Where the individual has an alternate SIL provider, that provider will work directly with Brightwater SDA in accordance with the Collaboration Agreement.

1. The Contact Centre triages enquiries against the eligibility criteria and collates relevant documentation for the Engagement Coordinator Disability Services.
2. The Engagement Coordinator reviews the documentation to identify eligibility and suitability for Brightwater Services, including an assessment to establish clinical and care requirements, financial eligibility, NDIS planning status and other information relevant for admission including other mainstream and NDIS funded service providers involved in service provision. The assessment process is conducted in liaison with the client, family and referring agency.
3. The Engagement Coordinator progresses eligible referrals to the relevant service representatives including SIL, SDA, and/or Capacity Building as appropriate and in alignment with the preferences of the referrer.
4. Service representative review: Each relevant service will review referral documentation for suitability and capacity of the program to provide services that meet the client's needs. This review may include requests for further information, change to a NDIS plan, provision of specific equipment or other items that may assist in facilitating successful admission. Where a potential client is requesting more than one Brightwater service, a consent to share information is required to enable collaboration between services.
  - Capacity Building Program: Brightwater NDIS and Community Services include a range of services including, but not limited to, therapy, support coordination and positive behaviour support. Participants may have their own circle of supports from other providers or may choose some Brightwater Capacity Building Services.
  - SIL: The SIL Team, including SIL Coordinator, Clinical Coordinator, and Funding Support Officer, are responsible for confirming client care needs and capacity of the SIL to provide the required support ratios and skilled clinical supports in the context of the proposed house(s). The SIL team is responsible for negotiating an agreed roster of care and facilitating the SIL Service Agreement with the client.
  - SDA: The SDA Tenancy Manager is responsible for vacancy management in SDA houses, including confirmation of SDA plan suitability, tenancy matching, site tours, and collaboration with the selected SIL provider. SDA Service Agreements and Tenancy Agreements are managed by the SDA provider. For more information about Brightwater SDA services including client matching, admissions process, and terms and conditions see the Brightwater SDA Handbook.
5. Where an individual is seeking admission to Piara Waters, once admission appropriateness is confirmed by all parties, including service provider(s), current residents, and the prospective client, the service representatives will collaborate with each other and the new client to facilitate the admission date and logistics.

## **Funding for Piara Waters Services**

All clients will require NDIS eligibility with plans to include funding for both SIL and SDA. Brightwater will work with each client's circle of supports through the plan review process to ensure individual plans reflect care requirements.

## Fees and Charges

### **Charges for SIL support**

These charges pay for the care workers to provide the care and support services. The pricing is determined by the NDIS Price Guide and applies to all clients - NDIS participants and non-NDIS clients (see the NDIS website for more information).

NDIS participants are charged the NDIS SIL funding amount specified in the NDIS plan, for the period specified, and consistent with the agreed schedule of shared support. Should you need more direct care support than what is funded, please discuss options with your Support Coordinator.

Non-NDIS clients are billed for services as per the Client Fees Agreement.

### **Daily fees for shared accommodation**

All Brightwater SIL clients living in SDA are charged mandatory daily board fees for food, cleaning, and other household consumables. The daily fee charged by the SIL provider is 50% of the maximum basic rate of the Disability Support Pension.

## Charges for SDA

The SDA funding allocation in an NDIS plan pays for the accommodation built to meet the SDA design standard. Brightwater SDA Houses at Piara Waters meet the requirements for high physical support. The pricing is determined by the NDIS Price Guide.

Daily board and lodging fees are required for rent and other property related costs, in line with SDA and community housing requirements. For information about Brightwater's SDA Service Fees please see [here](#) or visit our website [brightwatergroup.com/disability/huntingtons-campus-piara-waters](http://brightwatergroup.com/disability/huntingtons-campus-piara-waters).

## Staffing Model

### Management Structure

Brightwater SIL specialises in services for adults with Huntington's Disease, acquired brain injury, and other types of Neurodisability. This service sits under the oversight of the Chief Operating Officer, the General Manager of Community and Operations Manager, SIL. The SIL service for people with Huntington's Disease is directly managed by a SIL Site Coordinator and Clinical Coordinator. Leadership within the service is demonstrated and promoted within members of the direct care team who have advanced skills and credentials to model appropriate care practice.

### Circle of Supports

The Brightwater SIL model of care is driven by the client and their circle of supports of which SIL care workers are a part, but not the only provider or stakeholder in the individual's life. Each SIL client has a graphic representation with names, roles and contact details to empower SIL support staff to actively engage with the relevant other supports (Figure 3).

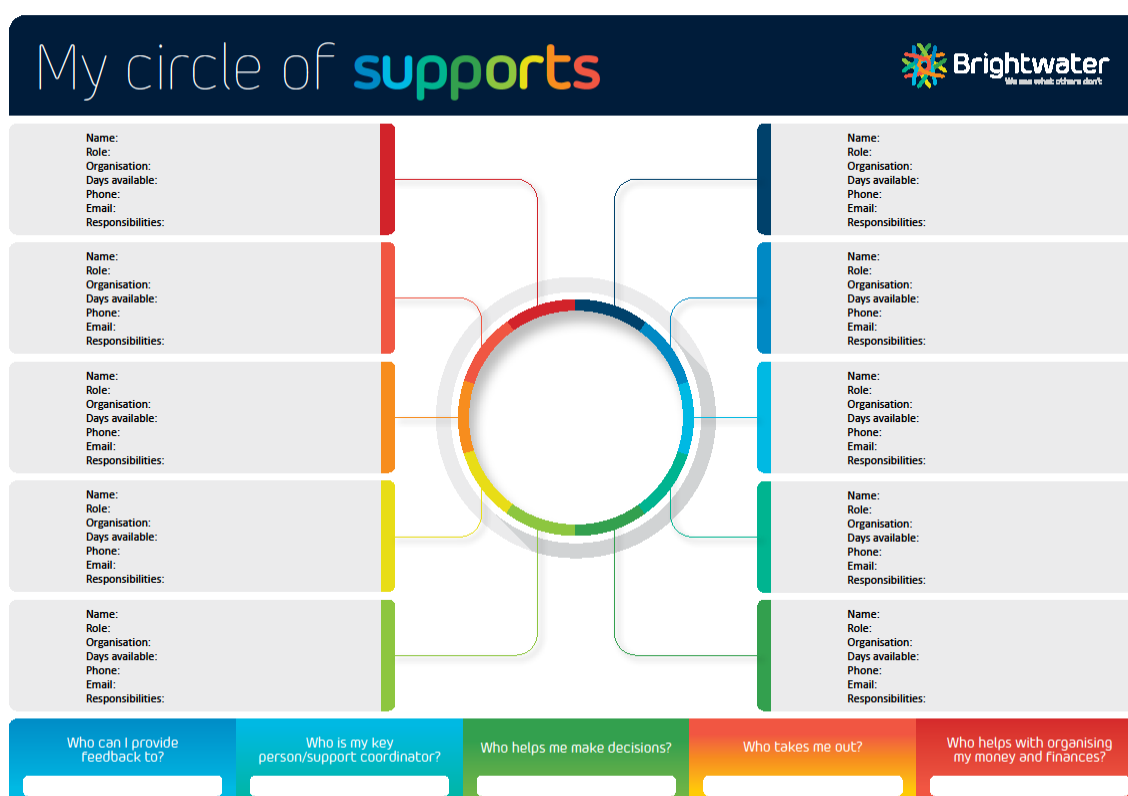


Figure 3. Circle of Supports

## NDIS Planning Process and Goal Attainment

All NDIS participants have independent choice and control to choose their NDIS funded services. Clients may choose Brightwater to deliver some or all available services including SIL, SDA, Support Coordination and Capacity Building.

The role of a Support Coordinator is to assist the individual and their representatives in managing their supports aligned with goals specified in their plan. There is potential for involvement from multiple providers. The Brightwater SIL team works closely with the client, their representative, Support Coordinator and Capacity Building Team to closely monitor and align their plan with their existing and evolving care needs.

Brightwater staff engage with social participation providers to ensure hand over of client information including changes to care requirements and encourage a social regime that is in accordance with client preferences and lifestyle. On occasions, when clients decline or are unable to attend social participation outings, funding for irregular supports is claimed.

## SIL Rostered Staffing

SIL offers 24/7 care both on a one-to-one basis and shared with other participants. At the Brightwater SDA houses in Piara Waters, Brightwater is both the SDA Provider and the SIL Provider in the first instance for most clients. There is potential for individual residents to choose daily individualised support or 24/7 SIL services from a provider other than Brightwater.

SIL includes direct care by disability support workers, with a ratio of staffing suited to meet the needs of the individuals in each house and with consideration of shared support across houses on the campus. Staff will be rostered to work across all houses, supporting each other on an as needs basis to facilitate client care and support, ensuring that care is delivered with the appropriate number of staff.

As mobility and swallowing function deteriorate with disease progression, people with Huntington's Disease have variable needs for 1:1 and 2:1 supports for activities of daily living such as transfers, meals, toileting, and bathing. At other times throughout the day individuals are supported with more light touch oversight to encourage independence with staff direct engagement driven by individual need and preferences. The roster of care may include sleepover shifts where suitable with client programs of support.

Brightwater SIL Care Workers are supported after hours with on call managers during the week and with Registered Nurses available for clinical advice when required. Weekend on call is staffed by a Registered Nurse who has oversight of all disability services. Neither registered nor enrolled nursing is funded by the NDIS for a regular shift basis, however, Enrolled Nurses are included in the program of supports where clinically practicable and achievable within the funding plan.

Brightwater Disability Support Workers and Enrolled Nurses are trained to deliver high intensity supports including severe dysphagia, complex bowel care, complex wound care, and enteral feeding as required. They work within their scope of practice and under the guidance of the Brightwater Clinical Governance Framework and NDIS Quality and Safeguards Practice Standards.

The initial service offering, when current Brightwater SIL clients transition to Piara Waters, is for Brightwater to continue as SIL provider for all clients. This should be the case until all clients have moved to their new homes and service routine has been established. Services will be delivered in the

context of the Brightwater SIL model of care for people with Huntington's Disease. It is the right of participants in SDA to select their SIL provider and Brightwater acknowledges that this may be the choice of some existing and future clients. We will work with clients and representatives and other providers to ensure that the homes continue to offer safe and supportive living environments through collaboratively seeking solutions as required.

### Staff Site Specific Training

To ensure Brightwater SIL staff are familiar with their clients, the living environment and service model, all staff participate in site specific orientation in addition to standard disability services orientation including principles of active support, positive behaviour frameworks, loading vehicles, and service delivery compliant to Quality and Safety Commission practice standards.

### Clinical Support

Individuals with Huntington's Disease have increasing requirements for clinical oversight as the disease progresses. Most NDIS participants also qualify for NDIS funded health supports which are delivered in a consultancy model not part of the daily roster of care. Clinically trained staff add value to the quality of care with particular attention to medications, wound care, continence plan management and training, and dietetics and are provided, as available within funding capacity and client care requirements.

#### *SIL Clinical Coordinator*

Coordination of clinical care for clients in Brightwater SIL for people with Huntington's Disease is overseen by a Registered Nurse who has specialty knowledge of Huntington's Disease.

Elements of clinical care include, but are not limited to:

- Medications
- Pressure care, wound prevention, and management
- Continence, bladder, and bowel function
- Dysphagia, weight, and nutrition
- Pain Management
- Positive behaviour support
- Falls injury prevention and management
- Clinical assessment and recommendations for management of changes in condition

This role is responsible for:

- Overseeing individual clinical elements of SIL assessments, care plan development, and implementation of care review, in consultation with the SIL Coordinator, client representative, and other members of the circle of support
- Ensuring that all care staff are appropriately trained and mentored to deliver supports for people with Huntington's Disease in line with individual care plans and role scope of practice, and that they have the understanding and resources to escalate matters where a client presents with changes in health, wellbeing, or behaviour.
- Managing service delivery performance of Enrolled Nurses
- Clinical incident investigations and follow-up
- Liaison with medical, nursing, allied health, and behaviour support specialists

### **Specialist Clinical Team**

Professional staffing support may include Speech Pathology, Physiotherapy, Occupational Therapy, Dietetics, Behaviour Support Specialists, and Registered Nursing. These supports require specified funding within the individual's plan. Individuals engage specialists from the service provider(s) of their choice which may be Brightwater's Capacity Building Team or another provider.

### **Primary Health Support – GP**

GP support is provided by the GP of choice for each client. Many clients from both Kailis and Ellison House access services of Dr Dananjaya (Danny) Bandara Dissanayake from Carousel Medical Centre, Unit 1 7-9 Pattie Street Cannington. Dr Danny has agreed to continue to support the clients following the move to Piara Waters. Dr Danny conducts regular onsite visits and provides support for managing clients' needs through telehealth appointments and additional visits when required.

All clients are offered the choice of attending Dr Danny, continuing with their existing GP, or sourcing a GP located in the Piara Waters vicinity.

The SIL Clinical Coordinator will liaise with all GPs regarding client care and to establish their availability to attend site if required, after hours arrangements and capacity and willingness to participate in end-of-life care.

### **Acute Medical Intervention**

Fiona Stanley Hospital is the nearest tertiary hospital to Piara Waters. It is expected that where the Emergency Department has availability, clients will be transferred via ambulance should they require acute intervention.

### **Mental Health Management**

Neurosciences support – 3 monthly visits to clients from a Neuroscience Psychiatrist with referral to community mental health services as required. Local community mental health service for day to day management of mental health is Armadale Mental Health Services [Armadale Health Service - Adult Mental Health Programs](#) Mead Centre.

### **End of Life Care**

End of life care is offered to all clients who choose to remain at Piara Waters and who can be supported to have a good death within the capacity of the available resources. Care is managed through a partnership between Metropolitan Palliative Care Consultancy Service (MPaCCS), Silver Chain and Brightwater. Brightwater provides hands on care and supported in accordance with the funding available in the individual's NDIS plan, MPaCCS offers training, education, assistance, and mentoring of staff including Advance Care Planning Support while Silver Chain delivers clinical care and support to manage pain, distress and other end of life symptoms.

### **Advance Care Planning**

When an individual has reached an advanced palliative phase their advance care plan (ACP) will be reviewed. The GP and guardian/s are notified, and a referral is sent to MPaCCS to support the conversations. The MPaCCS team may include a Consulting Doctor, Clinical Nurse or Social Worker in accordance with the individual case requirements. The updated ACP will be uploaded to Clinical Manager once signed off by the individual and their Guardian.

### **Active End of Life Support**

Where a client is starting to exhibit signs of deterioration, the GP and Guardian/s are advised. MPACCS should then be contacted to assist with symptom/identification/management recommendations and staff support (education) as needed. If the person stabilises, MPACCS will remain engaged for approximately 2 weeks, then will discharge them if no further input is required. Where symptoms are concerning the MPACCS consultant may recommend medication adjustments and introduce other treatments as needed.

If active input is required, MPACCS will continue to be present in the monitoring of symptoms until a point where the person is terminal. Through assessment they will liaise with facility staff and GP to hand over care by referring to Silver Chain Hospice when the client is suspected to have short weeks/days to live.

Silver Chain Hospice will continue to assess and support with ongoing symptom management that will be negotiated with the Clinical Coordinator and SIL Coordinator through client end of life, with Brightwater Enrolled Nurses providing care within their scope of practice and situational training as required. Where the person is thought to be near end of life but has stabilised, Silver Chain will remain engaged for 2 weeks and will be discharged if remains so. A new referral will need to then be provided by the GP if the client deteriorates again.

### **Pharmacy and Medication Administration**

All clients are responsible for the cost of their own medication and for making those payments directly with the pharmacist. Clients may choose their own pharmacist or can choose to have their medications managed by the Brightwater endorsed pharmacist.

Clients who choose to use their own pharmacist will be supported to manage their medication using paper-based signing sheets. Once completed these signing sheets will be scanned and uploaded into Clinical Manager.

The Brightwater endorsed pharmacist's electronic medication system is connected to the Brightwater's Medication Administration documentation system operated via tablet devices on site. For these clients all medication management and signing will be conducted through this system.

Where clients have capacity and choose to do so they are supported to self-administer medications using either webster packs or sachets. For those clients who require support with medication administration, medication competent support workers will assist with the administration as per Brightwater Policy/Procedure.

### **High Intensity Supports**

High intensity Supports are identified in the NDIS Quality and Safeguarding Practice Standards as those supports provided to NDIS participants who require more specialised, health-related support. The support required is described in a support plan and developed for the participant by an appropriately qualified health practitioner. Disability Support Workers play a role in implementing these plans, and usually work under direction of the Health Practitioner. These supports represent some of the highest risks for participants, workers, and others. Specific additional skills and knowledge are required to deliver high quality and safe supports in these areas. High intensity supports that may potentially be required by clients living at Piara Waters will be considered and managed on a case-by-case basis through collaboration of the SIL Coordinator, Clinical Coordinator, with the Client and their

representative and circle of supports. Brightwater staff may provide supports within their designated scope of practice and the Brightwater Clinical Governance Framework.

High intensity Supports may include:

- Enteral Meals and PEG Management
- Severe Dysphagia
- Complex Bowel Care
- Complex Wound Care
- Urinary Catheters
- Subcutaneous Injections
- Diabetes

## **Active Support in SIL**

In addition to the physical impact related to the manifestation of Choreiform (involuntary) movement and impaired ability to swallow and communicate, people living with Huntington's Disease also experience, amongst other changes, cognitive decline, deterioration in socialisation skills, visual perceptual impairment, and metabolic disturbances. Delivery of care can be complex and must consider not only the common presentations seen with onset of Huntington's Disease but also each person's individual preferences, lifestyle, and personality. Supported risk taking includes a balanced approach between personal choice and safety, determined in full consultation with the individual, and their family and/or substitute decision maker(s), and is demonstrated by offering individualised choice and strategies in daily activities such as mobilisation, dietary change related to swallow, health management and community access. Care plans must be developed in consultation with the person and their families and regularly reviewed and updated to accommodate changing needs.

## **Approach to Restrictive Practices**

Brightwater discourages the use of restrictive practices and aims to reduce and ultimately eliminate their use. Brightwater works to promote individualised and alternative strategies, where possible, that best meet the needs of clients. If a restrictive practice is deemed as necessary, it will be Authorised and implemented as part of the client's behaviour support plan.

## **Occupancy Management**

The role of occupancy management sits with the SDA provider. As the SIL provider, Brightwater SIL teams will work closely with the SDA team to review vacancies and client movement to other houses that may be requested by the client or recommended by the SIL provider.

People with Huntington's Disease may experience rapid decline which initiates urgency for transition to an alternative program of supports or exploration of alternative accommodation. They may pass away quickly and unexpectedly or may continue palliation with support delivered both by the SIL provider and external health providers as required.



## **Technology and Digital Transformation Enablement**

Staff will be supported to respond to immediate client need through a hard-wired nurse call system that will send notifications via mobile phone. Each staff member will carry a mobile phone enabling them to all receive real time notification of both individual client requests through the nurse call system and staff colleague responses to these calls. Mobile devices such as phones and tablet devices will be integral to client care including providing records of care. These devices will also enable staff to directly record client progress notes, forms, and charts, monitor pain, and document medication administration with real time communication to pharmacy.

## **Hospitality**

Brightwater SIL services support individuals with Huntington's Disease through progression of the disease to be involved as much as possible in food preparation and the meal experience, and in maintaining the cleanliness of their home.

## **Meal Management**

The board component of the daily board services fee includes funding to purchase food for basic meals (excluding prescribed supplements). Clients who can eat standard food textures will prepare all meals in their house with support as needed. People with Huntington's Disease all develop Dysphagia over time, with many developing severe Dysphagia requiring significant modification to food texture. Brightwater has qualified staff and commercial grade equipment to prepare plate modified textured foods in house 6 for distribution to other houses as required.

A trained chef will be employed to prepare meals on site for clients who require specialised food preparation such as vitamised meals. Lunch and dinner meals will be managed on cook chill basis with them being prepared up to 4 days in advance and frozen. Meals may be ordered from an external vendor as required when the chef is on leave.

The Chef will provide daily supervision, training, and education to staff in food preparation, meal service, and meal presentation consistent with Brightwater's daily menu guides. They will ensure that a diverse range of dietary meal options are catered for and available to clients. The Chef will coordinate the timely delivery of meals to house kitchens for meal service, supervising and collaborating with Support Workers to ensure meals are served to clients in a timely manner consistent with client needs, at the correct temperature and are well presented.

Clients who do not require specialised meal preparation will be supported by Disability Support Workers to select meals, purchase food, and cook in their homes.

## **Laundry and Cleaning**

Direct care staff will provide spot cleaning for work and floor surfaces and ensure that clients are supported to maintain clean and tidy living environments. Clients will be supported by direct care staff to launder their personal clothing and small items within the house.

Hotel services staff will be employed to complete soiled linen washing for each house and regular household cleaning across each of the houses on a rotational and as needed basis. Staff providing linen and cleaning management will have oversight of deliveries and maintenance of the back of house facility.

Heavier cleaning will be managed through contracted services.

The Chef will be responsible for maintaining cleaning standards for the kitchen, equipment, and Butler's Pantry in House 6, conducting daily and weekly checks and cleaning schedules. They will provide advice to support staff to maintain kitchens and equipment in other houses.

## Equipment

Clients are responsible for funding individualised equipment including assistive technology that may be prescribed by their Allied Health Practitioner and funded through their NDIS plan. Brightwater works collaboratively with client and circle of supports to ensure that proposed equipment is suitable for the environment, can be integrated into the client care plan, and can be safely used by staff. The prescriber of assistive technology is responsible for arranging any appropriate training for care staff to use equipment and is responsible for facilitating ongoing maintenance and repairs.

## Consumables

Clients are responsible for the funding of consumable items such as nutritional supplements, continence support products, and wound care products. Brightwater SIL services include support to order consumables from the nominated NDIS registered vendor selected by each participant.

## Sleepover for Visitors

Brightwater values supporting clients to maintain family and social connections. All houses are equipped with an overnight assistance room in which a bed may be provided to accommodate overnight visitors under specific circumstances as agreed with the client, housemates, SDA and SIL provider. The presence of a visitor should have minimal impact on the wellbeing of clients and ability of staff to do their job. All overnight visitors should be a single visitor with a minimum age of 18 and should be a close significant other, preferably a family member.

## References

- (UK), H. D., & Healthcare, S. A. (TBC). *Huntington's Disease Association Standards of Care*. Liverpool, UK: Huntington's Disease Association (UK).
- Australian Huntington's Disease Associations. (2020). *Huntington's Disease and Disability Care: Submission to the Disability Royal Commission*. Retrieved November 2022, from <https://huntingtonsnswact.org.au/wp-content/uploads/2020/07/HD-and-Disability-Care-Disability-Royal-Commission-Submission.pdf>
- Cartwright, J. (2017). *Living well with Huntington's Disease: Community of Practice Framework a Guide for Practitioners and Providers*. Perth: Huntington's Disease Community of Practice Western Australia. Retrieved from <https://www.huntingtonswa.org.au/resources/Living-well-with-Huntingtons-Disease-WEB-VERSION-23NOV2017.pdf>
- Cubis, L., Davis, E., Loy, C., Winkler, D., & Douglas, J. (2022). *One size does not fit all: A qualitative investigation into the housing needs and preferences for people with Huntington's Disease*. Summer Foundation. Melbourne, VIC: Poster.
- HDSA. (2011). *A Caregiver's Guide to Huntington's Disease*. New York, NY: Huntington's Disease Society of America. Retrieved from <http://hdsa.org/wp-content/uploads/2015/03/A-Caregivers-Guide-to-HD.pdf>
- HDSA. (2014). *Caregiver Guide for Mid to Late Stage Huntington's Disease: For Long-Term Care Facilities and In Home Care Agencies*. New York, NY: Huntington's Disease Society of America.

- HDSA. (2014). *Understanding Behaviour in Huntington's Disease*. New York, NY: Huntington's Disease Society of America. Retrieved 2022, from <http://hdsa.org/wp-content/uploads/2015/03/Understanding-Behavior.pdf>
- National Disability Insurance Scheme. (2022, July 25). *Specialist Disability Accommodation Operational Guideline*. Retrieved November 2022, from [ourguidelines.ndis.gov.au: https://ourguidelines.ndis.gov.au/supports-you-can-access-menu/home-and-living-supports/specialist-disability-accommodation](https://ourguidelines.ndis.gov.au/supports-you-can-access-menu/home-and-living-supports/specialist-disability-accommodation)
- Pollard, J. (2010). *Caregivers Handbook for Advanced-Stage Huntington's Disease*. Dublin, Ireland: Huntington's Disease Association of Ireland. Retrieved from <https://www.huntingtonswa.org.au/resources/Caregivers-Handbook-for-Advanced-Stage-HD.pdf>
- Summer Foundation. (2022). *Budgetary impact of timely specialist disability accommodation payment approvals*. Discussion Paper. Retrieved November 2022, from [https://assets.summerfoundation.org.au/pdf\\_offload/2022/08/Budgetary-Impact-of-timely-specialist-disability-accommodation-payment-approvals-web.pdf](https://assets.summerfoundation.org.au/pdf_offload/2022/08/Budgetary-Impact-of-timely-specialist-disability-accommodation-payment-approvals-web.pdf)
- Willer, B. S., Allen, K., Anthony, J., & Cowlan, G. (1993). *Circles of Support for Individuals with Acquired Brain Injury*. Buffalo, NY: Rehabilitation Research and Training Center on Community Integration of Persons with Traumatic Brain Injury. Retrieved from <http://brightnet/dis/Shared%20Documents/Interesting%20Articles/Circle%20of%20Support%20-%20Dr%20Barry%20Willer%202014.pdf>



**Brightwater Central**

2A Walter Road West,  
Inglewood, WA 6052

ABN 23 445 460 050 ACN 612 921 632

📞 08 9202 2800

📠 08 9202 2801

✉ [welcome@brightwatergroup.com](mailto:welcome@brightwatergroup.com)

🌐 [brightwatergroup.com](http://brightwatergroup.com)