



tŷ hafan
Children's Hospice

Statement of Purpose

Approved by Board: February 2023
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Introduction

Tŷ Hafan opened its doors for the first time in January 1999, providing specialist palliative care to children in Wales with life-shortening conditions, and support to their families.

A life-shortening condition (sometimes known as a life-limiting condition) is a condition for which there is no reasonable hope of cure and from which children will die. Some conditions cause progressive deterioration, meaning that the child becomes increasingly dependent on parents and carers.

Tŷ Hafan places the needs of children with life-shortening conditions and their families, at the heart of everything we do. Services are provided at our purpose-built hospice in Sully on the south Wales coast and across our diverse community, in hospitals, local venues and family homes.

A registered charity, Tŷ Hafan is substantially reliant on the generosity of the public for the generation of funds to enable the provision of its care services, which are free at the point of contact for families. Some funding is made available by the Welsh Government and through individual commissioning arrangements with health boards and local authorities.

How is Tŷ Hafan regulated?

Tŷ Hafan is regulated by Healthcare Inspectorate Wales ('HIW'). HIW is the independent inspectorate and regulator of health care in Wales.

HIW's Chief Officer is based at the following address:

Healthcare Inspectorate Wales
Welsh Government
Rhydycar Business Park
Merthyr Tydfil, CF48 1UZ
Telephone: 0300 062 8163
Email: hiw@gov.wales

Healthcare Inspectorate Wales undertakes regular announced inspections as well as additional unannounced inspections. Following an announced inspection in October 2021, their latest report is available by visiting the Healthcare Inspectorate Wales website at <http://www.hiw.org.uk>.

As the Registered Provider, Tŷ Hafan presents this Statement of Purpose, which complies with Schedule 1, Regulation 6 of The Independent Health Care (Wales) Regulations 2011 and supersedes the Statement of Purpose dated June 2020.

This Statement of Purpose provides an outline of the services offered by Tŷ Hafan and the responsible persons:

Jason Foster Director of Finance	Sian Middleton Head of Clinical Governance and Service Improvement/Acting Director of Nursing and Clinical Services
Responsible Individual Tŷ Hafan	Registered Manager (application pending) Tŷ Hafan
Hayes Road Sully Vale of Glamorgan CF64 5XX	Hayes Road Sully Vale of Glamorgan CF64 5XX
Email: jason.foster@tyhafan.org Tel: 029 2053 2200	Email: sian.middleton@tyhafan.org Tel: 029 2053 2200
HIW registration number: HIW/00327 Registered Charity No: 1047912	HIW registration number: HIW/00327 Registered Charity No: 1047912

‘The registered provider’ means a person who is registered under Part II of The Act as the person carrying on an establishment or agency or is an organisation. Tŷ Hafan as an organisation is the registered provider. ‘The Act’ refers to the Care Standards Act 2000.

‘The responsible individual’ is a director, manager or secretary or other officer of the organisation and is the person whom the organisation has given notice to the appropriate office of the registration authority as being responsible for the supervision and management of the establishment (Regulation 10 (1) (2) (3) (4)).

‘The registered manager’ is an individual appointed by the registered provider to manage the establishment (Regulation 11 (1) (2) (3)).

Vision

“A Wales where every child with a life-shortening condition lives a fulfilling life, supported with the compassion and specialist care they and their family need.”

Purpose statement (Mission)

“No family should have to face the unimaginable loss of their child alone. With children and families at the heart of all we do, we provide free care and support in our hospice and in the community, offering a lifeline throughout the child’s short life, at end of life, through bereavement and beyond.”

Tŷ Hafan’s delivery of palliative care services is underpinned by the definition promoted by Together for Short Lives (2017), the national umbrella charity for children’s hospices:

“Children and young people who require palliative care can be cared for in various settings: in hospital, at home, or in a children’s hospice. The aim is to promote the best possible quality of life and care for every baby, child or young person with a life limiting condition and their family. Giving families real choice is key to this approach; a choice of place of care; a choice of place of death; a choice of emotional and bereavement support; and putting the child and family at the centre of decision making, to enable them to have the best quality of life, and death, possible.”

Treatment, Facilities and Services

Care and support services

Tŷ Hafan provides a range of clinical care and holistic support led by a multi-disciplinary team of healthcare professionals including a children's palliative care consultant. This includes respite, therapies, symptom management and end of life care services.

Tŷ Hafan's approach to care is holistic. It begins with a needs-based assessment that identifies the child's palliative care needs and the needs of their immediate family. A person-centred plan of care is developed in partnership with the child and family. Plans are focused on enriching the child's short life and addressing the physical, social, emotional, and spiritual elements of palliative care.

The bespoke care plan may include elements such as:

- family support
- outreach services
- hospice respite for short break care
- symptom management
- emergency and/or end-of-life care.

Care and support for families extends into bereavement and beyond.

Tŷ Hafan's care services team (including Tŷ Hafan's GP services) follow the clinical treatment plans (including medication regimes) established by the child's lead paediatrician, and where appropriate, in conjunction with the All-Wales Tertiary Paediatric Palliative Care Team. Any changes to the child's plan of care made by Tŷ Hafan's paediatric palliative care consultant is contemporaneously documented and conveyed to the lead paediatrician in a timely manner.

Tŷ Hafan's service provision is provided by a nursing and clinical services team and a family wellbeing and partnerships team.

Nursing and clinical nursing services

Many of the children receiving Tŷ Hafan's care services have complex health needs and require a range of clinical procedures and/or complex drug regimes. Children may or may not have cognitive function. Care is managed and delivered by a multi-disciplinary team made up of registered nursing and therapy professionals, supported by skilled non-registered support staff working to agreed competency models.

The delivery of care at Tŷ Hafan is, supported by relevant protocols, policies, and procedures. These are reviewed within a three-yearly cycle, and/or as regulations require and/or evidence-based practice evolves.

Registered nurses undertake the following practical procedures in relation to medicines management and wider care needs:

- the administration of medication regimes, which include oral, percutaneous, subcutaneous, nasogastric, topical, sublingual, intramuscular, gastrostomy, jejunostomy, rectal and nebulised routes
- subcutaneous medication via syringe drivers
- tracheostomy care
- gastrostomy, jejunostomy and nasogastric tube feeding
- NIPPY and BIPAP non-invasive ventilation
- oxygen therapy
- cough assist, suction and other respiratory therapeutic regimes
- where supported by the child's health board, blended diet via gastrostomy

Specific treatments

Tŷ Hafan provides only those care services within the scope of its regulation as an independent hospital and those consistent with its role as a children's hospice.

If a treatment requested by a clinician or other healthcare professional cannot be delivered safely and within the scope of Tŷ Hafan's registration, an alternative venue for delivering the treatment will be sought. For example, it may be more appropriate for the treatment to be provided within an acute hospital setting, where appropriate support from Tŷ Hafan's clinical team may be given.

Tŷ Hafan will work in partnership with the referring clinician to ensure a safe alternative for treatment is agreed in consultation with the child, where possible, and/or with the child's family or guardian(s).

Medical provision

Medical Model

Tŷ Hafan has a layered integrated medical model giving 24-hour medical cover providing different levels of expertise and specialism.

In-house Paediatric Palliative Care Consultant

Tŷ Hafan's paediatric palliative care consultant is a joint appointment between Tŷ Hafan and Cardiff & Vale University Health Board. The consultant is part of the tertiary paediatric palliative care team and supports the 24 hour on-call consultant rota. Having formed important links with secondary care health board paediatric consultants, the post-holder facilitates continuation of seamless clinical care and support. The consultant provides clinical oversight for children resident at the hospice and, when requested by consultant colleagues, will review, and provide clinical consultations in the community.

General Practice (GP) Services

Tŷ Hafan has a service level agreement with a local GP service, West Quay Medical Practice. A GP visits the hospice Monday to Saturday and can be contacted at other times as required.

Tertiary Paediatric Palliative Care

24-hour on call support is provided by the All-Wales tertiary paediatric palliative care team.

Cardiff and Vale Out of Hours GP Service

Additional non-specialist level support is available through the Cardiff & Vale out-of-hours GP service.

In the event of an unexpected deterioration relating to more complex paediatric palliative care symptom management, the GP out-of-hours service can discuss individual cases via telephone with a paediatric palliative care consultant and the hospice has access to local hospitals.

Referral pathways

There are established referral pathways for both routine and emergency admissions to the service, including emergency transfers from the local hospitals.

Quality and governance

Clinical care at Tŷ Hafan is underpinned by a clinical governance framework. Corporate governance is overseen by the board, which delegates the operational delivery of care services to the chief executive. In turn, the chief executive delegates day-to-day responsibility for care services to the director of nursing and clinical services and director of family wellbeing and outreach services.

Clinical governance is monitored via the clinical governance committee, which is chaired by an appropriate clinically qualified trustee.

The clinical governance committee meets on a quarterly basis and provides assurance to the board on matters pertaining to care.

In line with the requirements of the Independent Health Care (Wales) Regulations (2011) Tŷ Hafan, as the registered provider, has allocated the roles of responsible individual ('RI') and registered manager ('RM').

The RI role is the director of finance. The RI assigns day to day operational clinical governance responsibility to the head of clinical governance who will provide assurances to the clinical governance committee and board that governance arrangements within care services meet regulatory and statutory requirements.

A key role of the RI is the collation of regular feedback from service users to underpin reporting to the regulatory body. Tŷ Hafan collects service user feedback on various platforms including facilitated closed Facebook groups and has a programme of RI visits taking place at six monthly intervals.

Tŷ Hafan uses feedback from families to inform service development and shape and inform advocacy initiatives, on issues that matter most to them.

The role of the RM is delegated to the director of nursing and clinical services who is responsible for ensuring the safe management of the service through the setting and monitoring of safe standards of care.

Hospice-based care

The hospice can accommodate up to ten children/young people. One of the ten beds is reserved for emergency end of life care.

Occupancy levels can vary depending on the type of care/support being delivered, the dependency of the children, and the associated level of staffing resource.

Service offered at the hospice

Respite

Respite is a term used to define a residential stay of varying length that allows parents/guardians and families to take a short break from the 24*7 caring responsibilities involved in looking after their life-limited child.

Parents and siblings can opt to stay at the hospice in separate family accommodation. While their child is resident, they have the freedom to visit the local area and continue to be involved in their child's care and activities to the extent they wish, or they may wish to return to the family home or go on holiday knowing their child is being cared for in a place they trust.

When siblings stay at the hospice, siblings are the responsibility of the parents or guardian. During the child's stay siblings are welcome and encouraged to join in activities. Skilled play workers facilitate sessions that are inclusive of all children. Parents and guardians should liaise with staff if a sibling requires support during a residential stay.

Step-down care

Children accepted for care at Tŷ Hafan are likely to require medical or surgical treatment in hospital from time to time. Tŷ Hafan may be able to assist with the child's recovery as part of a negotiated step-down plan. This can also provide an opportunity for parents to become more confident in the administration of new procedures and care regimes.

Emergency admission and symptom control management

Tŷ Hafan will always try and to respond in a timely way to a request for admission due to a breakdown in care or support, where there is an escalation

of symptoms, or where the need for a medication and/or treatment regime review would be supported by a hospice stay.

End-of-life care and symptom management

A priority will be placed on providing care in the final days, weeks, or months of a child's life. Sometimes the child is known to Tŷ Hafan for many years, or it may be a new child requires admission from home or a hospital setting, for example intensive care and/or neonatal units.

End-of-life care includes the management of symptoms and care after death, and support is offered to the entire family. Where end-of-life care or symptom management necessitates an emergency admission it will take priority over respite care.

Collaborative working with health and social care partners

Tŷ Hafan is committed to working collaboratively with health and social care partners to support all children in Wales who have a life shortening condition.

In the event of a request for an extended, assessment of the child needs and the impact on services being available to other children and families will be made. All admission requests look at the child's individual needs and urgency to meet that need. Commissioning arrangements for more lengthy stays due to unforeseen or complex social issues may lead to a bespoke plan.

Other elements of hospice, therapy, and outreach palliative care services

Physiotherapy

Tŷ Hafan provides a physiotherapy service at the hospice and provides advice to families and/or carers on positioning and movement. Physiotherapy services include general stretches/movements, hydrotherapy, and respiratory care. The physiotherapist provides training to ensure the wider team have the required skills to support the delivery of a physiotherapy care plan, as needed.

The hospice physiotherapist liaises with community and hospital physiotherapists to ensure that programmes of physiotherapy can continue in community and during hospital-based care, and that any changes or recommendations are shared.

Hydrotherapy

An on-site hydrotherapy pool is available for resident and non-resident children and their families. This is a purpose-built pool offering hydrotherapy sessions, therapeutic play, and family fun. Benefits of hydrotherapy include pain relief, relaxation, ease of movement and a sense of freedom, particularly for children who have very complex seating needs.

Families who may otherwise struggle to find suitable facilities can enjoy fun time together, enjoying skin to skin contact in a warm and pleasant and safe environment.

Out-patient access to the pool is by appointment only.

Occupational therapy

Tŷ Hafan provides an occupational therapy service supporting families, children, and young people to do the everyday activities that are important to them, using specific interventions to minimise the impact of disability and, where possible, to promote independence.

This might include professional guidance regarding equipment or adaptations and finding ways to make everyday life easier. Occupational therapy facilitates engagement and participation which in turn improves health, wellbeing, and quality of life.

Play

Tŷ Hafan employs specialist play staff and has a wide range of specialist and generic play equipment to enable children to learn, communicate, develop, and have fun through the medium of play.

Play is a vital element in the lives of all children and is important for their wellbeing and development.

A suite of electronic devices and equipment is available to be used by children, young people and their families' accessing services in the hospice.

Where a needs-based assessment identifies a requirement for a therapeutic intervention, such as music, play or complementary therapy, either as a standalone or alongside the individualised plan of care, this can be provided in the child's home, at school, in the hospice, or in the hospital environment.

Our play team equips and manages a toy and leisure library that can be accessed by all families who receive care from Tŷ Hafan. A wide range of toys and equipment can be loaned to the child and family either in their home or hospital settings.

Music therapy

Music therapy is available both at the hospice and on an outreach basis. Referrals for music therapy are made on a needs-led basis. Music therapy offers children a range of benefits including the ability to communicate, relax, learn, express their individuality, and have fun through the medium of music. Music therapy has also been shown to be beneficial to children and young people coming to terms with their own mortality and offers a medium to express fear, anxiety, and hope.

Complementary therapy

Children and families may benefit from using supplementary treatments, in conjunction with medical, nursing and physiotherapy interventions, to alleviate distressing symptoms. The service is provided by qualified complementary therapists and is available in-house and as outreach in the community following assessment.

The service is available for children, young people, and their families, and bereaved families.

Education

Continuing education during a hospice care is encouraged where appropriate.

Where required a nominated member of the care team will liaise with the child's school prior to visits to ensure that educational needs continue to be met.

Communication between schools and Tŷ Hafan is actively encouraged to share specialist knowledge and skills relating to individual children. Where appropriate and feasible, children are supported to attend school during their hospice stays.

Transition services

When a young person reaches the age of 16, they transition from children to adult services, Tŷ Hafan works with young people and their family to navigate and support this transition. This can often be a time of great uncertainty and create a range of anxieties, with skilled support and access to specialist transition support clinics the impact of the transition can be minimised.

Family Support

Living with the reality that a child has a diagnosis of a life-shortening condition can place an enormous strain on all members of the family.

The child, parents (or guardians) and siblings may need social, emotional, spiritual, and practical support to ensure that they continue to function as an effective family. All members of care services collaborate to provide this support.

The family support team may offer specialist support or advice which addresses the social, emotional, and practical needs of the family. These services can be offered in the child's home, school, hospital or at the hospice and an 'on call' service is available 24 hours a day, 365 days a year.

Support for the family may be provided in therapeutic or support groups or in individual sessions by a skilled team of family support practitioners. Dedicated support services for siblings, and mums and dads are provided both in the hospice and community settings.

Specialist counselling or play therapy is available to families throughout the child's life and throughout bereavement. Play therapy is a specialist intervention delivered as a course of interventions facilitated by registered therapists; it enables children to express hopes, fears and anxieties through play and the desired outcome is to enhance wellbeing and resilience. Counselling provides the same opportunities for adults and young people through the medium of talking therapies.

Bereavement support

The family can be supported immediately after the death of their child and through bereavement in the hospice, in hospital, in the community or the child's home.

A dedicated family support practitioner working as part of the multi-disciplinary team will support discussions around end-of-life care and bereavement. There may be a series of visits or conversations over a prolonged period and/or support provided at the end stages of the child's life and this support be offered for as long as required.

Families no longer requiring active bereavement support, are offered ongoing contact from the family support team. This may take the form of drop-in groups, bereaved family events or occasional one-to-one emotional support.

All bereaved families are invited to biannual services of remembrance which are held at Tŷ Hafan for the families of the children known to the Charity who have died. These services are hosted in June and December at the hospice sanctuary and in the memorial garden and are accessible virtually.

Decision Making and Consent

Tŷ Hafan upholds the principle formulated in Article 12 of the United Nations Convention on the Rights of the Child (UNCRC 1989) that when adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account. In accordance with this right, Tŷ Hafan will give due weight to the opinion of the child in accordance with the age, mental capacity, and maturity of the child.

Care services staff will support the autonomy of every child to make decisions, ensuring each child is an active participant in all aspects of their care planning; from small decisions such as what to wear, to choices at end of life where they are able.

Children are supported to express their views or choices with the use of communication aids, specific language systems, parent support, skilled staff or independent support as needed. This includes supporting access to advocacy services, either independently or with the help of care services.

Care services staff will obtain a valid consent from the person with parental responsibility for all palliative care interventions delivered by care services in accordance with extant legislation and guidance.

Care services staff respect the autonomy of each child gaining consent as referenced below, explaining, and involving them in all care activity,

The consent of the child will be sought from those individuals under sixteen deemed to be *Gillick Competent* and all those over sixteen with capacity in accordance with Section 8 of the Family Law Reform Act 1969.

Information governance

Tŷ Hafan adheres to the UK General Data Protection Regulation (GDPR)

Where we require consent for data processing, consent will be sought from children under sixteen deemed Gillick competent and from those over sixteen with capacity.

Service user engagement and feedback

Tŷ Hafan is committed to evolving its service provision and its facilities to enable the delivery of safe, effective, and personalised care.

The views of, and feedback from children and their families underpin the development and running of Ty Hafan's services. Families are asked for real-time feedback to enable us to monitor the quality and safety of care services, to ensure care quality standards are upheld and any service improvements are implemented.

Feedback can be given via a questionnaire or through service users' feedback survey. Service users can also ask to speak with a lead nurse on duty or with a member of the care services management team. Comments are also welcomed electronically on Tŷ Hafan's website <https://www.tyhafan.org/contact-us/>.

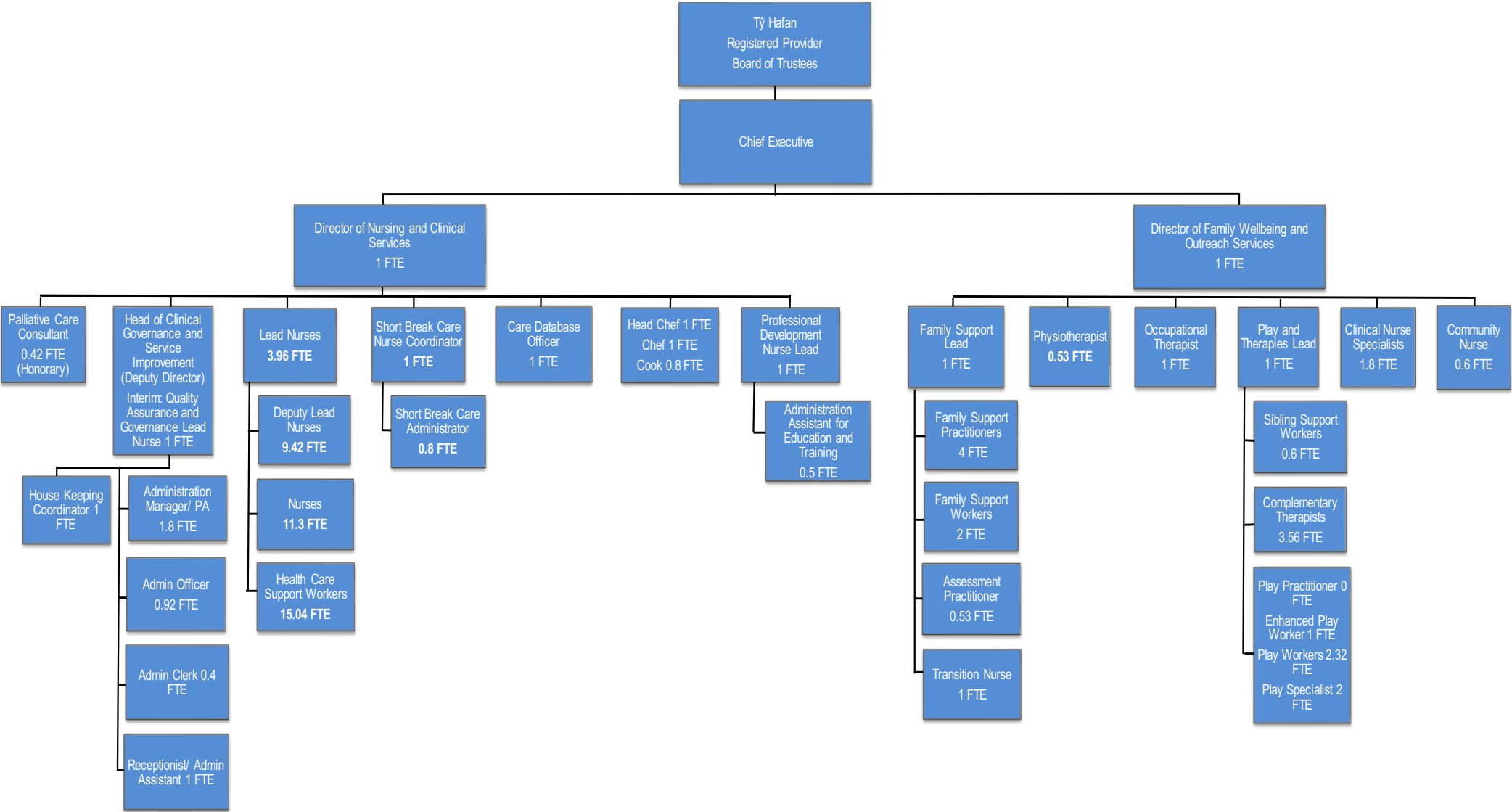
All families are allocated a named point of contact, and are offered the opportunity to participate in facilitated, closed Facebook groups which also offer peer support.

Making suggestions, raising concerns and complaints

Tŷ Hafan aims to ensure the care it delivers is in line with the National Minimum Standards for Independent Health Care Services in Wales. Where families are concerned that Tŷ Hafan has fallen short of these standards or should a family wish to raise a concern or make a specific complaint about any of Tŷ Hafan's services, a complaints policy is in place to support this.

Tŷ Hafan is also aware that sometimes individuals wish to make complaints anonymously. Whilst Tŷ Hafan will undertake the same process of investigation, it does mean that the organisation is unable to resolve the issue 'face-to-face' or provide feedback to individual or family concerned.

Organisational Structure



Qualifications and experience of senior Tŷ Hafan staff and medical practitioners at time of publication

Name	Qualifications and Experience
<p>Jason Foster Director of Finance Responsible Individual</p>	<p>Qualified Accountant (ACCA) Director of Finance and Deputy CEO for Tŷ Hafan. Over 25 years of experience in senior finance roles across various sectors. Helped to ensure the charity remained financially and operationally sustainable through the pandemic. Leading role in governance and risk management for the Charity. Previous roles have included UK lead for US steel trading company and Head of Reporting in a national marketing agency.</p>
<p>Sian Middleton Head of Clinical Governance and Service Improvement/Acting Director of Nursing and Clinical Services Acting Registered Manager</p>	<p>Qualifications Bachelor of Nursing (BN) First Class Honours. Bachelor of Midwifery (BMid) First Class Honours. 15 years' experience in nursing and midwifery roles gaining expertise in clinical governance and service improvement, with particular focus on bereavement support, high risk maternity care, risk management, clinical audit and medication management. Care and management experience has been gained in a variety of settings including District Nursing Teams, community palliative care teams, high and low risk maternity care, and triage assessment units. More recently delivering clinical leadership in a large independent hospital providing specialist care for clients with complex neurological disorders and acquired brain injuries.</p>
<p>Tracy Jones Director of Family Wellbeing and Outreach Services</p>	<p>Registered social worker. 30 years of experience in statutory and third sector social care with focus on children with complex medical conditions and specialist fostering support. Extensive experience in safeguarding. Specific interests in family wellbeing and resilience, supporting siblings and unpaid carers and encouraging service user participation.</p>
<p>Dr Megumi Baba Hospice Consultant in Paediatric Palliative Medicine (part-time) All Wales Lead for Transition in Palliative Care</p>	<p>Having completed specialist training in Paediatric Palliative Medicine in Cardiff in 2014, Dr Baba worked as the medical director at Charlton Farm Children's Hospice and consultant for Children's Hospice South West before moving back to Cardiff in June 2016 to take up a part time consultant post at Tŷ Hafan Children's Hospice, whilst undertaking a part time</p>

	position as All Wales Lead for Transition in palliative care at Cardiff and Vale University Health Board.
Dr Rhodri Lewis General Practitioner	Qualified in medicine 2000 has undertaken several hospital appointments including SHO in paediatrics and Paediatric Neurosurgery. Dr Lewis has been a General Practitioner with West Quay Medical Centre (formerly High Street Surgery) since 2004, becoming a partner in 2005. Dr Lewis has been a hospice GP since 2006 through a contract with West Quay Medical Centre.

Tŷ Hafan's specialist palliative care services are delivered by a multi-disciplinary team who have the following qualifications at the time of publication:

RN Adult Nursing RN Child Nursing RN Learning Disabilities RNSCPH Specialist Community Public Health Nurse Registered social worker Physiotherapist Occupational Therapist Play Therapists Complementary Therapist Music Therapist	
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A full list of the professional qualifications held by care services staff is available on request.

This document and any other information about Tŷ Hafan care services can be provided in alternative formats or languages on request. Such requests will likely incur a short delay as alternative language and formats are produced when requested to meet individual needs. Please contact the registered manager should you require any assistance.