

# **Statement of Purpose**

Approved by Board: 16 June 2020

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**Version Number: 12** 

Tŷ Hafan offers free of charge specialist palliative care services for children in Wales with life limiting conditions who may not reach adulthood, and supports their families during life, at end of life and through bereavement.

For the purpose of this Statement of Purpose, the term "life limited" refers to children who have a health condition for which there is no reasonable hope of cure and for this reason would not be expected to live beyond their eighteenth birthday.

Care services are offered in the community and at the purpose-built hospice in the Vale of Glamorgan which is registered for ten places and where the emphasis is on providing a homely environment whilst maintaining its status as a regulated independent hospital.

## Who is Tŷ Hafan Regulated by?

Tŷ Hafan is regulated by the Healthcare Inspectorate Wales and their Chief Officer is based at the following address:

Healthcare Inspectorate Wales

**Government Buildings** 

Rhydycar Business Park

Merthyr Tydfil, CF48 1UZ Telephone: 0300 062 8163

Email: hiw@gov.wales

As an independent organisation providing healthcare, Healthcare Inspectorate Wales undertakes regular announced inspections and additional unannounced inspections. The latest reports from these inspections are available on request or by visiting the Healthcare Inspectorate Wales website at <a href="http://www.hiw.org.uk">http://www.hiw.org.uk</a>.

Tŷ Hafan, as the Registered Provider, 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 November 2015. This Statement of Purpose provides an outline of the services offered by Tŷ Hafan.

Deborah Ho	Hayley Humphries
Director of Care	Head of Governance and Quality
Interim Responsible Individual	Registered Manager
(pending full application being	Tŷ Hafan
approved)	
Tŷ Hafan	
Hayes Road	Hayes Road
Sully	Sully
Vale of Glamorgan	Vale of Glamorgan
CF64 5XX	CF64 5XX
Email: deborah.ho@tyhafan.org	Email: hayley.humphries@tyhafan.org
Tel: 029 2053 2200	Tel: 029 2053 2200
Fax: 029 2053 2821	Fax: 029 2053 2821

HIW registration number: HIW/00327	HIW registration number: HIW/00333RM
Registered Charity No: 1047912	Registered Charity No: 1047912

<sup>&</sup>quot;The Act" means the Care Standards Act 2000.

'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 Responsible Individual' is the person to whom the organisation has given notice to the appropriate office of the registration authority who is a Director, manager or secretary or other officer of the organisation and is responsible for the supervising 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).

## **Aims and Objectives**

Tŷ Hafan launched in January 1999 to provide free of charge specialist palliative care to children with life limiting conditions, and support to their families, throughout Wales. Tŷ Hafan has the following Vision and Mission.

#### Vision

"A Wales where all children who may die in childhood live a fulfilling family life."

#### Mission

"To offer a high standard of free care to children in Wales who may die in childhood in order to enrich their quality of life, and support to their families during life, at end of life and through bereavement."

Tŷ Hafan's delivery of palliative care services is underpinned by the definition promoted by Together for Short Lives (2017):

"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 services

Our total approach to care begins with an agreed needs-based assessment of each child's palliative care requirements and the needs of his or her immediate family. A tailor-made individual programme of care is developed in partnership and agreement with the child and family, to enhance quality of life, addressing the physical, social, emotional and spiritual elements of palliative care. This programme of care might include family support, outreach services, hospice care for short break care, symptom management, emergency or end of life care with support continuing beyond to bereavement services.

Tŷ Hafan's care services of are consultant led offering clinical and holistic care within a regulated establishment, where care services staff assess, implement and evaluate comprehensive and multi-disciplinary plans of care. The treatment and medication regimens are established by the child's lead paediatrician and where appropriate in conjunction with the all Wales tertiary paediatric palliative care team. Specific symptom management and care regimes are followed by the care services team and GP services engaged by Tŷ Hafan. Any changes to the child's regime made by the paediatric consultant employed by Tŷ Hafan is contemporaneously documented and conveyed to the lead paediatrician in a timely manner.

## 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 regimens. These aspects of care are managed by a multi-disciplinary team made up of regulated registered nursing and therapy professionals supported by non-registered support staff working to agreed competency models. Care services are delivered to agreed national and organisational standards, supported by relevant protocols, policies and procedures that are reviewed within a three yearly framework or as regulations require and as evidence-based practice evolves.

No care services staff will carry out clinical or therapeutic procedures unless they have been trained and assessed as competent to do so.

Registered nurses and where deemed appropriate following additional training and assessment of competence, experienced health care support workers, undertake the following practical procedures in relation to medicines management and wider care needs:

- the administration of medication regimens, 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 (following appropriate risk assessment).

## **Specific Treatments**

Tŷ Hafan can only provide those care services which it is able to provide within its regulation as an independent hospital and which it would be expected to provide as a children's hospice. As health care develops and enhanced health care professional roles emerge, Tŷ Hafan will support change, in compliance with the relevant guidance and standards set out by regulatory professional bodies and supported by the regulator Healthcare Inspectorate Wales. There may also be circumstances where Tŷ Hafan is working with the clinician or other healthcare professional and can support the administration of a specific specialist treatment not routinely provided at the hospice, but it is considered clinically appropriate and safe to do so, following consultation with the clinician and an assessment of risk. Where this is deemed appropriate by the care services senior management team, a full training and competency program will be put in place to support safe practice.

However, there may be occasions when a clinician or other healthcare professional, with responsibility for the clinical care of the child, decides that a specific treatment should be administered which cannot be delivered at Tŷ Hafan as part of the care services it provides. This may be because it is more clinically appropriate for it to be provided within an acute hospital setting and/or where the staff at Tŷ Hafan do not hold the required competency and it is not possible to provide the training to the required standards to ensure safe care.

In this instance Tŷ Hafan will always work in partnership with the referring clinician to ensure a safe alternative for treatment is agreed in consultation with the child and the child's family.

Where there is a clinical need for a medical review Tŷ Hafan will ensure the child is reviewed by a medical professional, either the hospice GP via the agreed service level agreement or the hospice consultant. Should this be out of hours, the on call paediatric consultant will be contacted and the GP out of hours service asked to attend where necessary. In the event of a lifethreatening situation hospice care team staff will undertake basic life support and an emergency ambulance will be called.

#### **Medical services**

Tŷ Hafan has previously been a nurse led model with medical cover for the children who are resident at the hospice provided by West Quay Medical Centre. In June 2016, Tŷ Hafan welcomed its first paediatric palliative care consultant in providing medical leadership for the clinical team. The consultant post is a joint appointment between Tŷ Hafan and Cardiff and Vale University Health Board with 0.4 consultant cover for Tŷ Hafan and 0.6 as Wales Lead for Transition. This post sits as part of the tertiary paediatric palliative care team; supports the 24 hour on-call consultant rota; has formed links with secondary care health board paediatric consultants; provides clinical care for

the children resident at the hospice and, when requested by consultant colleagues, will review for clinical consultation in the community.

Tŷ Hafan also holds a GP service level agreement which forms part of a structured approach to a robust medical model of care for the hospice. This combined with the 0.4 consultant hours and input from the tertiary paediatric palliative consultants will ensure that Tŷ Hafan is able to provide medical cover throughout the week. On the occasions when the Cardiff and Vale out of hours service is required, Tŷ Hafan nursing staff are able to access support from the service for routine out of hours GP work, for example pyrexia. Where there is an unexpected deterioration relating to more complex paediatric palliative care symptom management, the GP out of hours service is able to discuss individual cases via telephone access with a paediatric palliative care consultant.

A referral pathway with the oncology department at University Hospital of Wales (UHW) has been developed. The hospice is seeing an increase in referrals from the oncology team. The Cardiff and Vale Community Paediatrician and Paediatric Neurologist have also expressed an interest in working more closely with the Tŷ Hafan consultant and clinical team. Where there is an identified need for specialist palliative medicine advice this can be provided by the Symptom Care Team based at UHW.

A professional update process (discharge summary) provides professional feedback of children and young people accessing services forging stronger links and healthcare benefits to health board paediatric colleagues, increasing access to advice and discussion around symptom management. The child's lead paediatrician continues to determine the medical care required by the child. However, whilst under the care of Tŷ Hafan's care services and the hospice paediatric palliative care consultant as part of the all Wales paediatric palliative care team, the hospice GPs, or a care services nurse if appropriate, will consult the lead paediatrician in regards to necessary medical interventions.

#### **Quality and governance**

Clinical care at Tŷ Hafan is underpinned by a robust governance framework. Corporate governance is overseen by the board of trustees, which delegates the operational delivery of care services to the chief executive. In turn the chief executive delegates day to day authority for care services to the Director of Care. Clinical governance is monitored via the Clinical Governance Committee, which is chaired by an appropriate clinically qualified trustee.

The Clinical Governance Committee monitors all elements of clinical governance including:

- risk management
- clinical audit
- education, training and continuing professional development
- evidence-based care and effectiveness
- patient and carer experience and involvement
- staffing and staff management

The Committee meets on a quarterly basis and provides an assurance report to the board.

In line with the requirements of the Independent Health Care (Wales) Regulations (2011) Tŷ Hafan, as the Registered Provider, has allocated the role of Responsible Individual and Registered Manager.

The Responsible Individual role sits with the Director of Care, aligned to accountability for the provision of safe and effective services which meet the needs of the client group. A key element is ensuring this is the ability to gain relevant feedback from service users to underpin reporting to the regulatory body. To support this Tŷ Hafan holds regular service user meet and greet groups at the hospice and across the south, mid and west Wales regions to ensure families are able to feed back their experiences.

The role of the Registered Manager currently sits with the Head of Governance and Quality to ensure management of the service can be safely enacted through the setting and monitoring of safe standards of care. The Registered Manager also ensures that processes are in place for service users to feed back their experiences following a stay at the hospice both by word of mouth at their one to one exit interviews, by the completion of a paper based questionnaire and now also by means of electronic feedback processes, which can be completed at the hospice or on their own mobile devices.

#### Hospice care

The hospice can accommodate up to ten children for overnight palliative care with or without parents and siblings who can be accommodated separately. From January 2020, the hospice is undergoing a phased refurbishment of its premises. This means that the availability of accommodation will be subject to change during this period.

#### Short Break Care

Short break care may be provided for children and families as part of their individual programme of care. The amount offered to each family will be determined by a needs-based assessment and the ability to fulfil the care needs required in a safe manner, however the minimum offer to each family is two short breaks in each year.

Resident siblings are welcome at the hospice, but must always be accompanied by a parent or family member who is eighteen years of age or over (a responsible adult). Siblings are welcome to join in activities and play workers will facilitate sessions that are inclusive of all children. Siblings should not be left unsupervised. Carers and parents should work with care services staff in ensuring their safety at all times. Staff supervision of siblings may be possible but if the care demands of children receiving palliative care are high, this may not be possible. Parents and carers should liaise with staff if there is a need for a sibling to be supported during a residential stay. If it is identified that a sibling needs extra support a referral can be made to the

sibling support service which offers therapeutic support via group work and individual sessions.

## Post-Surgical Convalescence

Many of the children accepted for care at Tŷ Hafan will also require medical or surgical treatment in hospital. Tŷ Hafan may be able to assist with the child's convalescence after this treatment. This can also provide an opportunity for parents to become more confident in the administration of new procedures and care regimes if such changes have been made during admission.

## Emergency Admission and Symptom Control Management

Tŷ Hafan will always make every effort to respond to a request for admission due to a social issue or where there is an escalation of symptoms or the need to review medication and treatment regimens would be supported by a stay at the hospice for the hospice consultant or the all Wales tertiary paediatric palliative care team to amend the treatment plan.

## End of Life Care and Symptom Management

Care is provided in the final days, weeks or months of a child's life. The child may be known to Tŷ Hafan for many years or it may be that they are new to the care services of Tŷ Hafan and require an admission from home or hospital including intensive care and neonatal units.

End of life care includes the management of symptoms and care after death and supports the whole family at this time. Where end of life care or symptom management necessitates an emergency admission it will take priority over short break care.

#### Collaborative working with health and social care partners

There may be specific requirements and requests made through a child's health board for healthcare provision over and above the allocated short break stays. Tŷ Hafan will assess a request based on the assessment of need in individual circumstances and if due to family crisis or clinical need will support with the offer of an extra short break, or hospice admission for clinical review. Where it is not possible for the relevant health board to return the child home due to capacity or complex social issues, an agreement may be drawn up whereby the health board will commission Tŷ Hafan care services within a bespoke plan.

## Other elements of hospice therapy and outreach palliative care services Physiotherapy

A physiotherapist is employed at the hospice to provide therapies across the seven-day service These include general stretches/movements, hydrotherapy, chest care and advice to all carers on positioning and movement. The physiotherapist always liaises with community and hospital physiotherapists to ensure that programmes of therapy continue in community and hospital-based care, and that any changes or recommendations are communicated. Physiotherapy services are available at the hospice throughout the week dependent on need and the physiotherapist will ensure staff have the skills to carry out routine physiotherapy as necessary.

## Hydrotherapy

Hydrotherapy sessions can be offered to children and families in a purpose built, accessible pool area. Hydrotherapy involves the use of water to alleviate pain and distressing symptoms, to create distraction for children, to give children a sense of freedom and movement. It can also be beneficial for the family allowing time together and close skin to skin contact. Families can access the hydrotherapy pool when not resident by contacting the hospice and booking a slot.

### Play Services

Play is a vital element in the lives of all children for their wellbeing and development. Tŷ Hafan provides specialist staff and a range of specialist and generic play equipment to enable children to learn, communicate, develop and have fun through the medium of play. A suite of electronic devices and equipment provided by Lifelites is available for service users: children, young people and their families, when accessing services in the hospice.

Play is supported by a toy and leisure library, which 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 in their home and hospital settings.

Where the needs-based assessment identifies a requirement for specialist play support or a therapeutic intervention such as music, or complementary therapy, either as a stand-alone or adjuvant to the individual package of care, this can be provided in the child's home, at school, in the hospice, or in the hospital environment.

## Specialist Play and Play Therapy

Children requiring specialist support from a health care play specialist can access this service based on assessed need. This support is provided by a suitably qualified experienced practitioner whose post is funded by Children in Need. Play therapy is not currently a service offered but we are working with health board colleagues to scope the need for such services and have access to a limited play therapy service should it be assessed as needed. We work closely with other providers of play therapy and can signpost families to other services.

#### Music Therapy

A music therapist is contracted to provide this service two days per week, both in the hospice and on an outreach basis, following assessment of need for individual children. Music therapy offers children the ability to communicate, relax, learn, express their individuality and have fun through the medium of music. Music therapy has 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. This service is provided both in-house and outreach in the community following assessment of need for children, young people and their families. Complementary therapy services are also available to be eaved families.

### Education

Education is encouraged where relevant during hospice care. If requested by a family, a nominated member from care services will liaise with the child's school prior to visits to ensure that educational requirements continue to be met. Communication is actively encouraged between schools and Tŷ Hafan in order to share specialist knowledge and skills for individual children and where appropriate children are supported to attend school during their hospice stays.

## Support for the family

Living with the diagnosis of a life limiting condition can place an enormous strain on all members of the family. The parents, siblings and child may need social, emotional, spiritual and practical support to ensure that they continue to function as an effective family. All members of care services contribute to providing this support.

Family support services may offer specialist palliative care 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 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. There are also dedicated support services for siblings, mums and dads provided both in the hospice and community settings.

#### **Bereavement support**

The family can be supported immediately after the death of their child and into bereavement in the hospice, hospital, in the community or the child's home. A dedicated family support practitioner will work as part of the multi-disciplinary team and support discussions around end of life care and bereavement. This may be a series of contacts and communications over a prolonged period as well as supporting at the end stages of the child's life. Following the death of a child the family will be supported for as long as required. When families no longer require active bereavement support they will be offered ongoing contact from the dedicated bereavement worker. This contact may take the form of drop in groups, bereaved family events or occasional one to one emotional support as necessary. In addition, all bereaved families are invited to biannual services of remembrance which are held at Tŷ Hafan for the families of the children who have died. These services are provided in June and December in the hospice sanctuary and the memorial garden.

# Arrangements for contacting relatives, friends and representatives during admissions to the hospice

At each admission to the hospice, Tŷ Hafan will require up to date contact details for contacting next of kin, or the person with parental responsibility. This is extremely important in case there should be a change in the child's usual routine or health status. A member of the care services team of Tŷ Hafan will make contact at the earliest opportunity.

Family and friends are always welcome to visit whilst a child is staying at the hospice. However, we request that families inform us in advance of any visits by family and friends and that they respect the privacy and requirements of other resident families and children. Tŷ Hafan does not routinely provide meals for visitors, although there is always plenty of tea, coffee and soft drinks available. Where family members would like extended family or friends to join them for a meal, this should be arranged in advance with the care services team and catering staff and is dependent on catering requirements on the day.

Family and friends are welcome to contact the hospice to enquire about the child and/or speak to the family, however we will need to carry out relevant identity checks prior to discussing any child in our care.

Reception staff will relay messages received on the hospice direct telephone number which is 029 2053 2200 in a timely manner, but there may be a delay during busy periods, therefore if the message is urgent, please convey this to the receptionist at the time of calling.

# **Privacy, Dignity and Respect**

Tŷ Hafan will treat all service users with the utmost dignity and respect. Where privacy is requested by a family, we will take into account the wishes and feelings of the child and family, however as a registered healthcare provider Tŷ Hafan has to uphold its duty of care and ensure the child's best interest remains paramount when discharging its duty of care.

In order to provide a safe and secure environment Tŷ Hafan uses a fob accessed system to enter the hospice. Families are asked to respect this and always enter the building by the official routes, using the sign in books where requested. Closed circuit television monitoring is installed at the entry barrier and entrance to the hospice. It is a system in which signals are not publicly distributed but are monitored, primarily for surveillance and security purposes.

Confidentiality forms part of our governance at the hospice and to support the confidential handover of patient identifiable sensitive information, a specific room with staff access only is used for handover reports between staff.

Tŷ Hafan always works in partnership with families and when a parent or carer wishes to provide all care including clinical and social care to their child, this will be agreed as part of a risk assessed care plan. Tŷ Hafan staff will need to monitor and document that care has been delivered in accordance with the plans whilst the child is resident at the hospice; this will all be done in partnership with the family.

The hospice environment is designed to promote privacy. Staff will ensure that any nursing or personal care is performed in the privacy of the child's room. Facilities for bathing, showering and toileting are also designed to ensure that the child's dignity and privacy are respected. Each bedroom has an internal lock, which is used during personal care but can be accessed externally in emergencies to gain entry.

Tŷ Hafan expects all staff to be treated with the same dignity, respect and courtesy as they demonstrate to our service users. Any concerns in relation to a child's care, or the behaviour of Tŷ Hafan staff should be brought to the attention of the person in charge. Any verbal or physical abuse of Tŷ Hafan staff will not be tolerated and where this occurs Tŷ Hafan reserves the right to end a short break care stay.

# **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 and maturity of the child.

Care services 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. The ability of each child to make such decisions will be taken into account according to the specific circumstance.

Children who need specific support to be able to express their views or choices will be provided with the appropriate communication aids, specific language systems, parent support, skilled staff or independent support to enable others to understand their choices. This includes supporting access to advocacy services, which they may do independently or with the help of care services.

Care services staff will respect the autonomy of each child by informing them of all care or procedures to be undertaken, ensuring they understand the nature of the intervention and are prepared for the intervention to take place.

Care services will obtain a valid consent from the person with parental consent for all palliative care interventions delivered by Care services in accordance with extant legislation and guidance. Consent for intervention will be obtained during a care needs assessment when a child is accepted for Tŷ Hafan care services.

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.

The General Data Protection Regulation (GDPR) requires Tŷ Hafan to produce a privacy notice stating how we will use a service user's personal and sensitive data and must have a version that is appropriately written for children to understand, using clear and plain language. 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.

Tŷ Hafan is committed to delivering care in partnership and agreement with the child and family, as well as in accordance with the child's primary physician. In the event of any dispute or disagreement about aspects of care delivery or the refusal of treatment, Tŷ Hafan will attempt to resolve the disagreement through discussion with the parents. Where this is not possible Tŷ Hafan will liaise with the relevant health and social care professionals and, where necessary, seek legal advice to resolve the dispute.

## Service user engagement and feedback

The comments and views of children, and their families underpin the development and running of care services. Families are asked for real time feedback immediately following each period of short break care to monitor the quality and safety of care services.

Feedback can be given via a questionnaire or through an electronic service users' feedback survey. Service users can also ask to speak with a lead nurse on duty or ask to speak with a senior member of the care services Management Team Comments are also welcomed electronically on the Tŷ Hafan website <a href="http://www.tyhafan.org/about-ty-hafan/contact-us">http://www.tyhafan.org/about-ty-hafan/contact-us</a>.

Tŷ Hafan appreciates that many families in Tŷ Hafan's care may have a longstanding relationship with the hospice and feel strongly about change. To support the future development of the service and any required change to the buildings and surrounding area, families are consulted by formal consultation on any significant change in provision or environment.

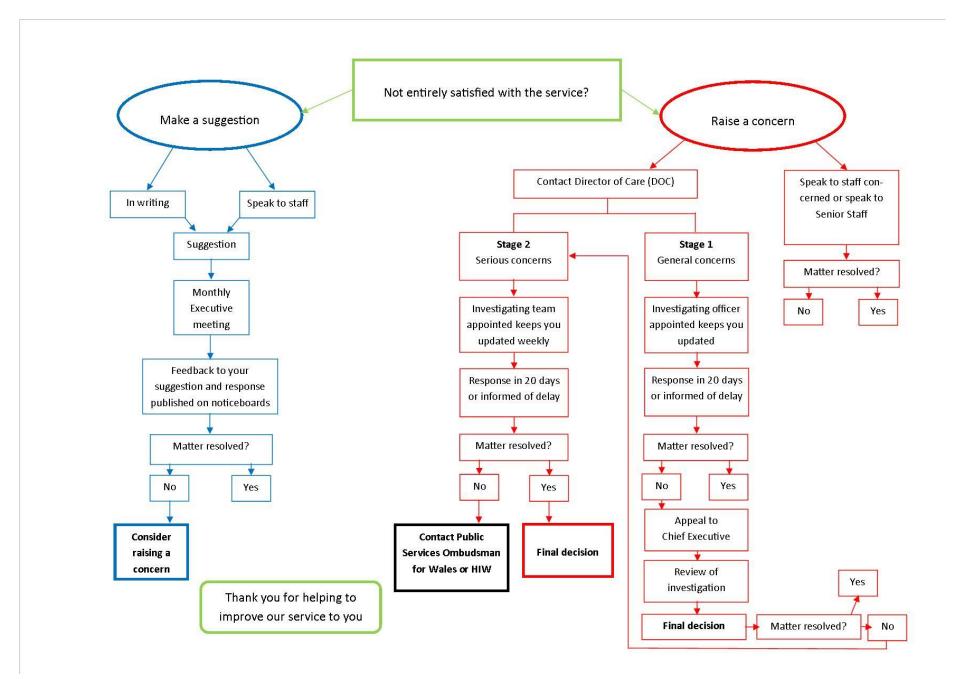
Care services senior management team also offers regular meetings with service users to ensure they have a voice in the planning and running of Tŷ Hafan and from time to time wider independent surveys may be undertaken to ensure we continue to meet the needs of eligible children and their families.

## Making Suggestions, Raising Concerns and Complaints Procedure

Tŷ Hafan aims to ensure the care it delivers is in line with the National Minimum Standards for Independent Health Care Services in Wales and to monitor and support this, Tŷ Hafan introduced the first Quality Assurance Framework assessment in 2018, which also includes service users' views. Where families are concerned that Tŷ Hafan has fallen short of these standards, or wish to make a specific complaint about any of Tŷ Hafan's services, a policy is in place to support the complaints process.

The procedure for making suggestions, raising concerns and complaints is set out in Tŷ Hafan's Complaints Policy, outlined in a leaflet available in the hospice and on the website <a href="https://www.tyhafan.org/contact-us">https://www.tyhafan.org/contact-us</a>.

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 individual concerned and the organisation are unable to resolve the issues 'face-to-face'.

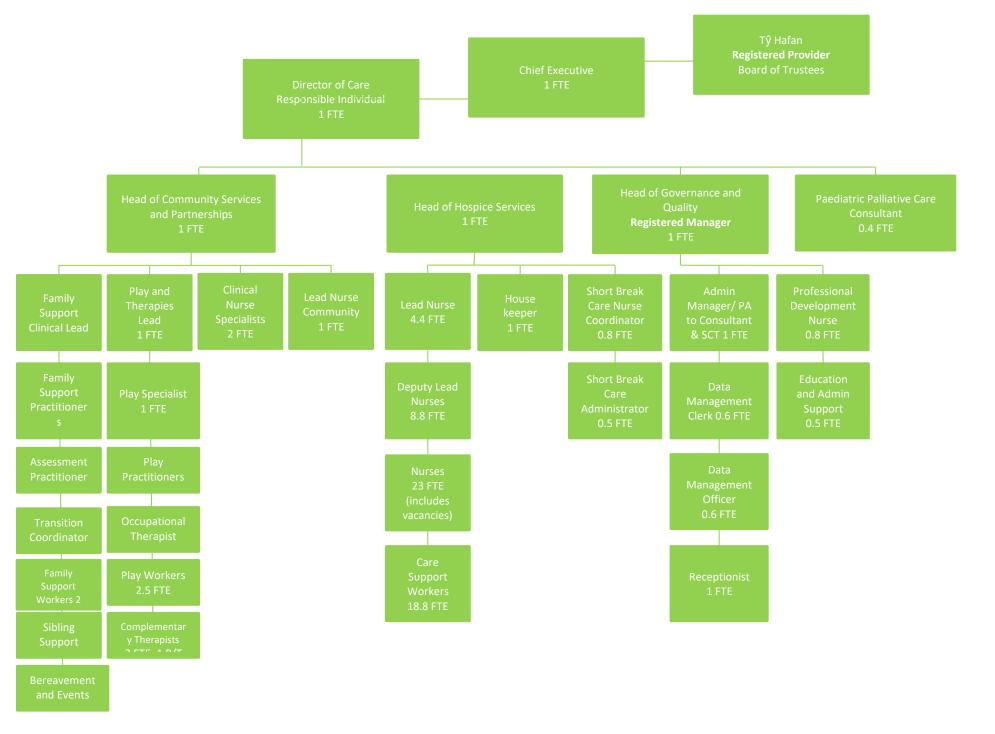


# **Organisational Structure**

A board of trustees, led by the Chairman, is the senior body of the organisation from which all authority is conducted either directly or through delegation.

The organisational chart illustrates the structure within care services. The board delegates responsibility for the operational delivery and quality of care services to the Chief Executive, who is the responsible individual and who in turn delegates day-to-day authority for the management and safe delivery of care services to the Head of Hospice Care Services.

Tŷ Hafan, as the Registered Provider, has appointed the Director of Care as the Responsible Individual and the Head of Governance and Quality as the Registered Manager.



Relevant qualifications and experience of senior  $T\hat{y}$  Hafan staff and medical practitioners at time of publication.

Name	Qualifications and Experience
Deborah Ho Director of Care	Deborah Ho is an experienced leader and health professional, and has worked in the palliative and end of life care for over 25 years. This includes working within the hospice sector as a Director of Patient Services and deputy Chief Executive. Deborah has also worked as a senior manager in vulnerability, accessibility and inclusion at a large financial services provider.  Qualified nurse  Degree and Masters level study in palliative care and hospice leadership.  Certificates in oncology nursing and training and development.  First hand experience as a Trustee at Ty Hafan.  Role of Responsible Individual for Ty Hafan.
Hayley Humphries Registered Manager	BSc (Hons) RN Child Neonatal nurse 2003-2005 alongside community children's nursing Tŷ Hafan 2005-2010 as children's nurse and nurse with shift leading responsibility Paediatric Emergency Unit, University Hospital of Wales 2010-2012 Returned to Tŷ Hafan 2012 as a children's nurse and then became a Care Services Team Leader in October 2012 to December 2014 Head of Governance and Quality, 2015 to 2018; Registered Manager and Accountable Officer for Controlled Drugs Chartered Management Institute, Strategic Leadership and Management, Chartered Fellow of CMI 2018 Current role is Head of Governance and Quality, including Role of Registered Manager and Accountable Officer for Ty Hafan
Dr Megumi Baba Hospice (part-based) Consultant in Paediatric Palliative Medicine All Wales Lead for	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

Transition in Palliative Care	Children's Hospice, whist undertaking a part time position as All Wales Lead for Transition in palliative care at Cardiff and Vale University Health Board.
Dr Rhodri Lewis General Practitioner (Lead Hospice Doctor)	MBBCh Qualified in medicine 2000 has undertaken a number of 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 the lead clinician since 2006 and is a member of the Managed Clinical Network for Paediatric Palliative Care.

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

RNadult Adult Nursing	14
RNchild Child Nursing	45
RNLearndis Learning Disabilities	3
RNSCPH Specialist Community Public Health Nurse	4

A full list of the professional qualifications held by care services staff is available on request.