

**Ty Hafan Childrens Hospice**  
**Hayes Road**  
**Sully**  
**CF64 5XX**

**Inspection 2009/2010**

**Healthcare Inspectorate Wales**

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17-19 March 2010	1. I M Roberts 2. F Edwards

## Introduction

Independent healthcare providers in Wales must be registered with the Healthcare Inspectorate Wales (HIW). HIW acts as the regulator of healthcare services in Wales on behalf of the Welsh Ministers who, by virtue of the Government of Wales Act 2006, are designated as the registration authority.

To register, they need to demonstrate compliance with the Care Standards Act 2000 and associated regulations. The HIW tests providers' compliance by assessing each registered establishment and agency against a set of *National Minimum Standards*, which were published by the Welsh Assembly Government and set out the minimum standards for different types of independent health services. Further information about the standards and regulations can be found on our website at: [www.hiw.org.uk](http://www.hiw.org.uk).

Readers must be aware that this report is intended to reflect the findings of the inspection episode. Readers should not conclude that the circumstances of the service will be the same at all times.

## Background and Main Findings

Tŷ Hafan originated as a purpose built building that would provide palliative care and support for children with life limiting conditions. As the catchment area is extensive – covering from N Ceredigion and N Powys southwards and in response to the growing needs of children and their families for a wider range of support, Tŷ Hafan, as an organisation, is increasingly providing a range of services for children and their families closer to their home. This was in the form of support and advice for the whole family, specialist therapy sessions e.g. music therapy, and organisation of parent and sibling support groups. This aspect of the service was outside the scope of this inspection.

The overall findings of the inspection were positive with evidence of increasing professionalisation of the service and organisation. Tŷ Hafan has embraced the changing landscape of palliative care in Wales as recommended by the Sugar Report <sup>1</sup>(2008) and the subsequent implementation report by Finlay (2008). <sup>2</sup>As a result of these reports and changes, Tŷ Hafan has been proactive in reviewing its services and policies. Substantial developments had taken place over the past two years: they had responded positively not only to the changing culture in palliative care but also to requirements made from previous inspections and comments made and issues raised by service users.

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<sup>1</sup> <http://www.wales.nhs.uk/sites3/docmetadata.cfm?orgid=831&id=116436>

<sup>2</sup> <http://www.wales.nhs.uk/documents/Palliative-Care.pdf>

The strength of the service stemmed from the knowledge and expertise that staff had acquired in palliative care of children since opening, however, they recognise gaps that still exist and that such learning is an on-going process. Recent developments included changes in structure and management arrangements of the wider organisation and Tŷ Hafan itself, review and refinement of policies and procedures, changes in the governance and management of the hospice and associated support services and the increased professionalism of the service and associated practice. The Registered Manager is now designated as Director of Care and has a much extended role that is predominantly associated with strategic development. As a result she has much less time to spend on the direct management of the hospice and fulfilling personally the statutory duties of a registered manager. Many senior managers and staff have been in post for several years and this has facilitated the change ensuring consistency and continuation of care for children and their families.

## **Information Provided**

A Statement of Purpose and a Patient's Guide were available principally for parents. These provided information about the service delivered and were reviewed at least once annually. The next review could usefully reflect the wider accepted definitions of palliative care and recognised general and specific charters for children's rights, and standards of service delivery specifically for children with life limiting and life threatening conditions and their families. This inclusion would clarify for all concerned the philosophy that underpins the care that is to be provided. The statement of purpose could also usefully indicate the range of children's needs that they can meet and the eligibility criteria for admission. As parents often shared in the care of their children whilst all were resident at Tŷ Hafan, the parents/patient guide could usefully indicate the nature of such arrangements and agreements to be made.

Some of the older children, as an activity had produced a photographic and text account of their experience of staying at Tŷ Hafan. This creative, informative and attractive booklet appeared to be sound foundation for a children's guide for similar aged children: such guides were unavailable at the time of the inspection. Consideration should be given to developing a patient guide which is appropriate for younger children. All guides should reflect the language, culture and understanding of the children concerned.

## **Quality of Treatment and Care**

Care was provided by a team of registered nurses with experience and relevant training in paediatric palliative nursing care and carers, most of who were trained to NVQ level 3, play workers, social workers, a music therapist and complementary therapist. Nearly all were well-experienced in palliative care. A GP from a local medical practice made thrice weekly routine visits to the hospice, he and his colleagues readily visited at other times and provided support, advice and assistance: this was a valued and effective partnership. Staff were supported by community based health care professionals e.g. physiotherapists and worked closely with Paediatric/Oncology Departments at hospitals in Cardiff and Swansea.

The staffing ratio at all times was minimum of 1<>1 with higher ratios provided when required. All children had an allocated link nurse and carer who took the lead in organising care, maintaining contact with the children, their families and relevant professionals.

As part of the ongoing professional development of the service, Tŷ Hafan had refined its admission criteria and process. Management and staff were clearer about the care and treatment that they could provide taking into consideration the expertise and knowledge of staff: they acknowledged that they could not meet all needs. Tŷ Hafan made clear in its Statement of Purpose that it was limited in the extent of invasive care it was able to provide at the hospice, such as the giving of chemotherapy and blood transfusions. As indicated above this document could also usefully reflect the criteria for admission and the full range of needs that can be met.

Referrals came from a variety of sources e.g. GPs, Paediatric Oncology Depts., Community Nurses, Social Workers and all were coordinated by one member of staff. Following receipt of all required information admissions were determined by a small panel that included senior managers and a medical professional – usually the lead GP from the local practice. Older children and their families were involved in the sharing of information from initial referral and subsequent assessment of need. Efforts were made to make this an on-going process following admission.

Care plans were prepared at each visit into Tŷ Hafan. Whilst containing most required factual information, it was agreed that further refinements would be appropriate to consider as part of the ongoing quality review of personal care records’.

Suggested improvements are:

- reflect a more holistic approach to care
- all aspects of clinical, physical, emotional, social, educational, cultural and religious needs required during that stay should be noted.
- individual objectives for each visit detailed
- details of specific needs of the child and the methods by which these were to be met and the persons involved in performing the identified action, including timescales.
- child’s specific needs for privacy
- child protection issues
- specific risk assessments undertaken in respect of the individual needs of the child over and above the routine ones of tissue viability, use of bed rails and manual handling.

The care plans and end of placement evaluation were not routinely prepared by the Senior Nurse but were always counter-signed by them. This arrangement and associated guidance should be reviewed to ensure consistency of practice and accountability.

Play workers organised day activities for children during their stay. This included creative activities at Tŷ Hafan and visits out to the community e.g. shopping, visits to the cinema, play-centres. Some children were able to continue attendance at school: this was not possible for those whose homes were some distance away. Children were supported in completing school work that they brought with them. As good practice, consideration could be given to the use of an education co-ordinator who could develop this aspect of service for all children resident, including siblings.

Clinical practice observed was considered to be appropriate and in keeping with current guidance on palliative and nursing care. Good practice was observed in relation to administration, storing and auditing of medication, including controlled drugs. There was also good practice in relation to infection control with excellent standards of hygiene and overall cleanliness of the premises. Clinical practice on each shift was overseen by the lead nurse and monitored by the Assistant Director of Care for Clinical Services and Director of Care through regular audits. This model appeared to be effective with evidence of learning through events where practice had not been to the required level. A new Clinical Governance framework was about to be introduced and this will be reviewed at the next inspection visit

Discussions indicated sensitivity of all managers and staff to the end of life care of children and support for families. The policies and procedures had recently been reviewed and amended with clearer documentation and agreements now being in place regarding end of life care. There was acknowledgement that this was a difficult time for all concerned. Families were offered and provided with bereavement counselling and support that could be on going. Staff were offered similar support. It is recommended that as good practice, after the death of a child under the care of Tŷ Hafan, a whole team formal debriefing is held to reflect, identify good practice and agree remedial action for "lessons learnt". All staff, during their induction would benefit from training in difficult discussions that need to take place in relation to this sensitive area of practice.

Feedback was sought from children and families at the end of each visit: there was however no systematic way of collecting, collating and evaluating the responses. This may be an area for future development.

Policies and procedures had been reviewed during the past year. Staff were familiar with the changes made with these being highlighted at the twice weekly handover meetings.

## **Management and Personnel**

The commitment of all managers and staff to their caring role was highly evident. All worked together effectively to provide individualised care for all children, support for their families and supporting others.

The Registered Manager was well experienced and had kept up to date with training and developments in the palliative care of children. She is now the Director of Care and has a predominantly strategic role within the wider organisation, only spending on average one day a week at Tŷ Hafan undertaking directly management and statutory duties. The day to day management of care at Tŷ Hafan was, at the time of the

inspection, undertaken by the Assistant Director of Care (Clinical Services): she was supported and assisted where necessary by the Assistant Director of Care (Professional Supplementary Services) who managed the community based outreach services. The Director of Care was in daily telephone contact with Tŷ Hafan and was kept informed of all developments regarding the care of the children. In light of the much extended role of the current Registered Manager, the organisation needs to review the appropriateness of one person having demanding dual roles and responsibilities.

Several of the staff had been in post for a number of years. They had a robust recruitment and selection process. Staff files sampled indicated that all required checks were undertaken including renewal of CRB's every 3 years. As good practice, consideration could be given to routinely undertaking telephone references in keeping with the ethos of "Choosing with Care" (Warner Report). Following appointment staff undertook an induction programme that was reported to enable staff to undertake their role appropriately.

All nurses had the relevant qualifications and experience, and were registered with the nursing professional registration body. They had the opportunity to update their training throughout the year, provided with clinical supervision and annual appraisals. All felt they had the necessary skills and knowledge to provide nursing care for children with a wide range of conditions with opportunities to undertake specialist training if appropriate. All interviewed felt very well supported by managers and colleagues.

Several care staff had or were in the process of completing NVQ level 3 in care. To date two separate weeks of training had been provided each year. This year, staff were piloting an e-learning programme. Health & Safety was the topic for the first quarter with Child Protection and Fire Safety Awareness to follow. Staff were often supported in attending specialist training that would enhance their skills and knowledge to work with children with specific conditions.

Whilst there had been no reported incidents necessitating a child protection referral, staff were provided with on-going training e.g. induction programme and next e-learning module. Qualified social work staff were assisting staff in reflecting on their practice and the need to be aware and provide safe care. This process was on-going.

## **Complaints Management**

Appropriate complaints information and associated policies and procedures were in place. No complaints that required investigation in accordance with the complaints policy had been received during this past year, although one long-standing complaint remained incomplete. Children were encouraged to make their own complaints with Tros Gynnal being accessed for advocacy support. In line with the comments made above, it would be useful to have complaints leaflets that are appropriate for children of all ages and understanding in their preferred language or usual means of communication. Most issues raised by children and their parents were satisfactorily resolved by informal means.

## **Premises, Facilities and Equipment**

As already noted there were good hygiene standards throughout. Appropriate systems were in place to dispose of clinical waste.

All maintenance checks appeared up to date and all damage/malfunctions promptly corrected.

All meals were freshly prepared in the appropriately equipped kitchen. A balanced menu was on offer at each meal time with special diets and individual preferences catered for. The catering staff conducted a weekly cooking session for children which was a popular activity with all concerned.

## **Records**

Appropriate records management systems were in place to ensure required details and entries are made in a timely manner. Records were safely stored with all staff mindful of the confidentiality policy and the legal requirements in respect of sharing information.

## **Research**

Tŷ Hafan was not involved in any specific research but contributed towards the gathering of routine statistics. Managers and staff contributed to the national organisations involved in the delivery of paediatric palliative care and the associated growing body of knowledge and expertise.

## **Achievements and compliance**

### **Areas of good practice and developments:**

- strong commitment of all managers and staff to delivery of a child-centred service
- commitment by all to on-going improvements and development of service with Tŷ Hafan
- extending services to children and their families within their own homes
- staff retention ensuring continuity and consistency of care
- development of a systematic clinical governance and auditing programme
- on-going improvements to the premises
- staff training and development programme
- commitment to on-going growth of expertise in children's palliative care



## Registration Types

This registration is granted according the type of service provided. This report is for the following type of service.

Description
<b>Independent Hospital - Hospice for children</b>

## Conditions of registration

This registration is subject to the following conditions. Each condition is inspected for compliance. The judgement is described as Compliant, Not Compliant or Insufficient Assurance.

Condition number	Condition of Registration	Judgement
1.	The number of persons accommodated shall not exceed 10.	Compliant
2.	Categories of care: <ul style="list-style-type: none"><li>• Specialist Care for Children between the Ages of 0 – 19yrs</li><li>• The staffing Notice dated 20 January 1999 is complied with. The Staffing Notice must be available on the premises at all times, for inspection or viewing by any person.</li></ul>	Compliant

## Assessments

The Healthcare Inspectorate Wales carries out on site inspections to make assessments of standards. If we identify areas where the provider is not meeting the minimum standards or complying with regulations or we do not have sufficient evidence that the required level of performance is being achieved, the registered person is advised of this through this inspection report. There may also be occasions when more serious or urgent failures are identified and the registered person may additionally have been informed by letter of the findings and action to be taken but those issues will also be reflected in this inspection report. The Healthcare Inspectorate Wales makes a judgment about the frequency and need to inspect the establishment based on information received from and about the provider, since the last inspection was carried out. Before undertaking an inspection, the Healthcare Inspectorate Wales will consider the information it has about a registered person. This might include: A self assessment against the standards, the previous inspection report findings and any action plan submitted, provider visits reports, the Statement of Purpose for the establishment or agency and any complaints or concerning information about the registered person and services.

In assessing each standard we use four outcome statements:

Standard met	No shortfalls: achieving the required levels of performance
Standard almost met	Minor shortfalls: no major deficiencies and required levels of performance seem achievable without extensive extra activity
Standard not met	Major shortfalls: significant action is needed to achieve the required levels of performance
Standard not inspected	This is either because the standard was not applicable, or because, following an assessment of the information received from and about the establishment or agency, no risks were identified and therefore it was decided that there was no need for the standard to be further checked at this inspection

## Assessments and Requirements

The assessments are grouped under the following headings and each standard shows its reference number.

- Core standards
- Service specific standards

Standards Abbreviations:

C = Core standards

A = Acute standards

MH = Mental health standards

H = Hospice standards

MC = Maternity standards

TP = Termination of pregnancy standards

P = Prescribed techniques and technology standards

PD = Private doctors' standards

If the registered person has not fully met any of the standards below, at the end of the report, we have set out our findings and what action the registered person must undertake to comply with the specific regulation. Failure to comply with a regulation may be an offence. Readers must be aware that the report is intended to reflect the findings of the inspector at the particular inspection episode. Readers should not conclude that the circumstances of the service will be the same at all times; sometimes services improve and conversely sometimes they deteriorate.

### Core Standards

Number	Standard Topic	Assessment
C1	Patients receive clear and accurate information about their treatment	Standard almost met
C2	The treatment and care provided are patient - centred	Standard met
C3	Treatment provided to patients is in line with relevant clinical guidelines	Standard met
C4	Patient are assured that monitoring of the quality of treatment and care takes place	Standard met
C5	The terminal care and death of patients is handled appropriately and sensitively	Standard met
C6	Patients views are obtained by the establishment and used to inform the provision of treatment and care and prospective patients	Standard met
C7	Appropriate policies and procedures are in place to help ensure the quality of treatment and services	Standard met
C8	Patients are assured that the establishment or agency is run by a fit person/organisation and that there is a clear line of accountability for the delivery of services	Standard met

Number	Standard Topic	Assessment
C9	Patients receive care from appropriately recruited, trained and qualified staff	Standard met
C10	Patients receive care from appropriately registered nurses who have the relevant skills knowledge and expertise to deliver patient care safely and effectively	Standard met
C11	Patients receive treatment from appropriately recruited, trained and qualified practitioners	Standard met
C12	Patients are treated by healthcare professionals who comply with their professional codes of practice	Standard met
C13	Patients and personnel are not infected with blood borne viruses	Standard met
C14	Children receiving treatment are protected effectively from abuse	Standard met
C15	Adults receiving care are protected effectively from abuse	Not applicable
C16	Patients have access to an effective complaints process	Standard met
C17	Patients receive appropriate information about how to make a complaint	Standard met
C18	Staff and personnel have a duty to express concerns about questionable or poor practice	Standard met
C19	Patients receive treatment in premises that are safe and appropriate for that treatment. Where children are admitted or attend for treatment, it is to a child friendly environment	Standard met
C20	Patients receive treatment using equipment and supplies that are safe and in good condition	Standard met
C21	Patients receive appropriate catering services	Standard met
C22	Patients, staff and anyone visiting the registered premises are assured that all risks connected with the establishment, treatment and services are identified, assessed and managed appropriately	Standard met
C23	The appropriate health and safety measures are in place	Standard met
C24	Measures are in place to ensure the safe management and secure handling of medicines	Standard met
C25	Medicines, dressings and medical gases are handled in a safe and secure manner	Standard met
C26	Controlled drugs are stored, administered and destroyed appropriately	Standard met
C27	The risk of patients, staff and visitors acquiring a hospital acquired infection is minimised	Standard met
C28	Patients are not treated with contaminated medical devices	Standard met
C29	Patients are resuscitated appropriately and effectively	Standard met

Number	Standard Topic	Assessment
C30	Contracts ensure that patients receive goods and services of the appropriate quality	Standard met
C31	Records are created, maintained and stored to standards which meet legal and regulatory compliance and professional practice recommendations	Standard met
C32	Patients are assured of appropriately competed health records	Standard met
C33	Patients are assured that all information is managed within the regulated body to ensure patient confidentiality	Standard met
C34	Any research conducted in the establishment/agency is carried out with appropriate consent and authorisation from any patients involved, in line with published guidance on the conduct of research projects	Standard met

**Service Specific Standards - these are specific to the type of establishment inspected**

Number	Hospice Standards	Assessment
H1	Arrangements for care in hospices	Standard met
H2	Palliative care expertise and training for multi-professional teams	Standard met
H3	Assessment of patient's and carer's needs	Standard met
H4	Delivery of palliative care	Standard met
H5	Records of care	Standard met
H6	Infection control	Standard met
H7	Resuscitation	Standard met
H8	Responsibility for pharmaceutical services	Standard met
H9	Ordering, storage, use and disposal of medicines	Standard met
H10	Administration of medicines	Standard met
H11	Self administration of medicines	Standard met
H12	Storage and supply of medical gases	Standard met
H13	Assessment and care of children	Standard almost met
H14	Qualifications and training for staff caring for children	Standard met
H15	Environment of care for children	Standard met

## Schedules of Information

The schedules of information set out the details of what information the registered person must provide, retain or record, in relation to specific records.

Schedule	Detail	Assessment
1	Information to be included in the Statement of Purpose	Met
2	Information required in respect of persons seeking to carry on, manage or work at an establishment	Met
3 (Part I)	Period for which medical records must be retained	Met
3 (Part II)	Record to be maintained for inspection	Met

## Requirements

There were no requirements made at this inspection.

## Recommendations

Recommendations may relate to aspects of the standards or to national guidance. They are for registered persons to consider but they are not generally enforced.

Standard	Recommendation
C 1	<p>The next review of the Statement of Purpose could</p> <ul style="list-style-type: none"> <li>○ reflect the wider accepted definitions of palliative care and recognised general and specific charters for children's rights, and standards of service delivery specifically for children with life limiting and life threatening conditions and their families.</li> <li>○ indicate the range of children's needs that they can meet and the eligibility criteria for admission.</li> </ul>
C 1	The Patient Guide for parents could reflect shared care arrangements
C 1	Develop children's guides reflecting age, culture and understanding in their preferred language and means of communication.
H 3 and H13	<p>Suggested improvements for care plans:</p> <ul style="list-style-type: none"> <li>○ reflect a more holistic approach to care</li> <li>○ all aspects of clinical, physical, emotional, social, educational, cultural and religious needs required during that stay should be noted.</li> <li>○ individual objectives for each visit detailed</li> </ul>

	<ul style="list-style-type: none"> <li>○ details of specific needs of the child and the methods by which these were to be met and the persons involved in performing the identified action, including timescales.</li> <li>○ child's specific needs for privacy</li> <li>○ child protection issues</li> <li>○ specific risk assessments undertaken in respect of the individual needs of the child over and above the routine ones of tissue viability, use of bed rails and manual handling.</li> <li>○ clarify who prepares, signs and is accountable for their completion.</li> </ul>
H 2	As good practice, after the death of a child under the care of Tŷ Hafan, a whole team formal debriefing should be held to reflect and identify good practice and agree remedial action for "lessons learnt".
H 2.7	All staff, during their induction would benefit from training in difficult discussions that need to take place in relation to this sensitive area of practice.
C6	Develop a systematic way of collecting, collating and evaluating the responses of children and their families about the level of service received.
C 9	As good practice, consideration could be given to routinely undertaking telephone references in keeping with the ethos of "Choosing with Care" (Warner Report).
C8	In light of the much extended role of the current Registered Manager, the organisation needs to review the appropriateness of one person having demanding dual roles and responsibilities.

The Healthcare Inspectorate Wales exists to promote improvement in health and healthcare. We have a statutory duty to assess the performance of healthcare organisations for the NHS and coordinate reviews of healthcare by others. In doing so, we aim to reduce the regulatory burden on healthcare organisations and align assessments of the healthcare provided by the NHS and the independent (private and voluntary) sector.

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