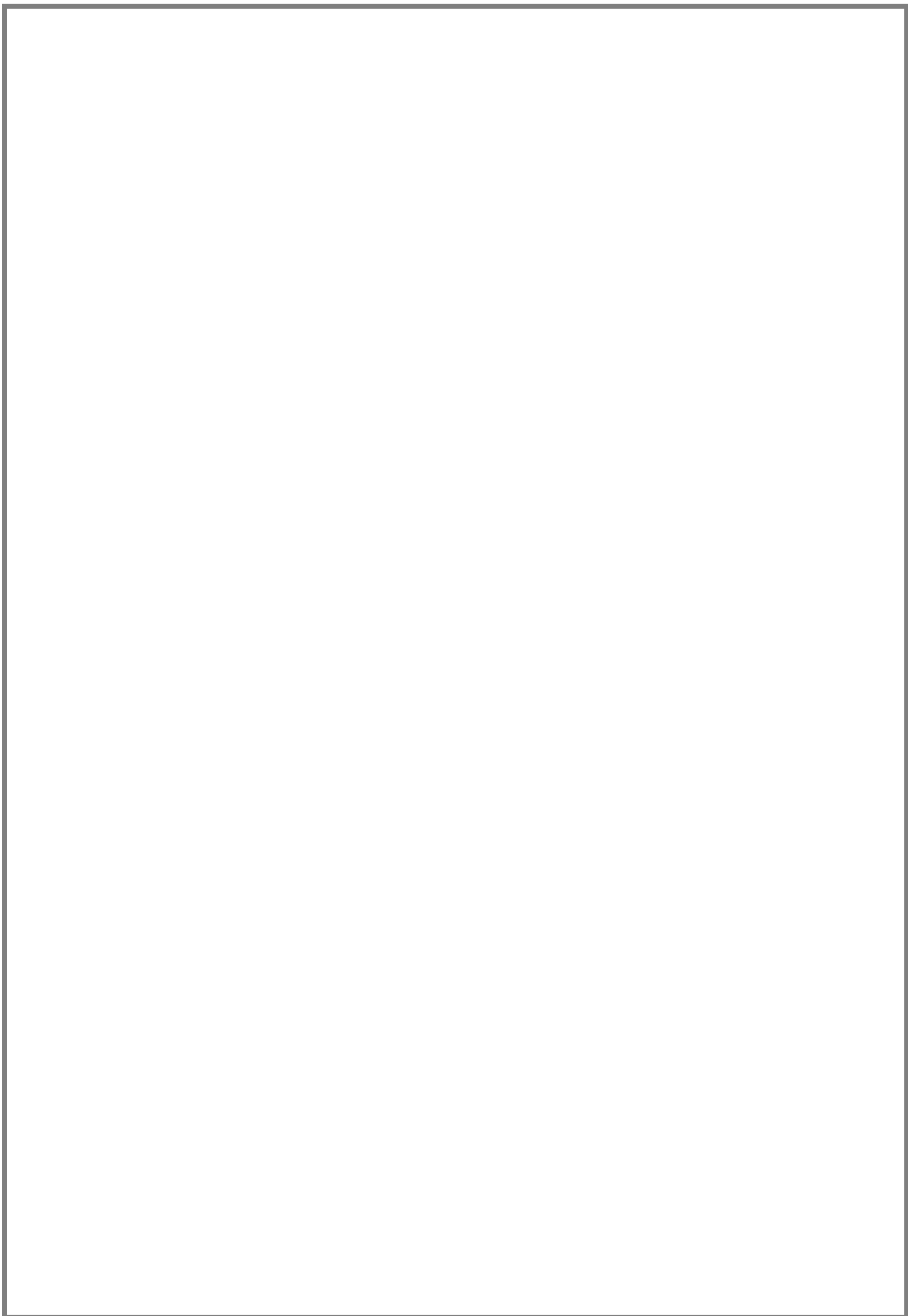




Parent and Family Guide to the services and support
provided by Tŷ Hafan

'Providing care, being there'

Approved: by the Board of Directors 16 March 2023



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Welcome to Tŷ Hafan

Everything we do at Tŷ Hafan is focused on children and families, on providing high quality family centred care and being there for children and families when they need it most. Our aim is to bring your child and your family the comfort, care and support you need in order to cope with the day to day challenges of living with a life-shortening condition.

Tŷ Hafan is a children's charity and we are grateful to our supporters and the people of Wales for the generosity which allows us to provide our expert children's palliative care free to your child and your family, wherever and whenever you need it.

You may already know something about Tŷ Hafan but we realise that it may be difficult to take in everything at a time when you are worried about the wellbeing of your child. This booklet gives you information we think it is important for you to know about Tŷ Hafan and the service we offer to families like yours who care for a child with a life-shortening condition.

Our care and support is delivered by a skilled and experienced team of staff who between them have many years of experience caring for children and families like yours.

We will work with you and other professionals involved in supporting your child and your family to give you the best care and support possible. We understand you may be feeling anxious about involving us in your lives because you don't know what to expect. We hope that this booklet answers some of your questions and takes away some of that anxiety. Our staff are friendly and approachable, so please don't hesitate to ask for more information or advice.

We have another document called the Statement of Purpose that sets out the information in this booklet more formally. The Statement of Purpose is available on our website at www.tyhafan.org. If you would like a paper copy, please ask a member of staff.

We look forward to providing you with specialist palliative care designed specifically to meet the needs of your family.

Sian Middleton

Director of Nursing and Clinical Services

Tracy Jones

Director of Family Wellbeing and Outreach Services

Section 2 | Introduction: Tŷ Hafan and Your Family

Tŷ Hafan is here for you because your child has been diagnosed with a life-shortening condition. You may have been living with this knowledge for some time or have just received this devastating news.

You are not alone. Whilst your child may be the reason for you receiving Tŷ Hafan's care services, we are there for you too, from the time of diagnosis and into what may feel to you like the unknown.

Tŷ Hafan is a charitably funded organisation, and the care and support we offer to you is free of charge. It will always be tailored to meet your child's needs and the needs of you and your immediate family. Your child does not have to stay at the hospice to benefit from our services; we provide outreach services at home and in community settings that include family and sibling support, play, and specialist therapies like music and complementary therapy.

We always begin by making an assessment of the individual needs of your child and members of your immediate family who are involved in the care of your child. This may be parents, grandparents, brothers and sisters, aunts and uncles and foster families.

When we know what you need, we will work with you to develop a plan of care for your child and family. We'll also include the other professionals who care for your child at home, school, or in hospital. This ensures that whether we offer you services at home or at the hospice, we are working with you as well as professionals around you and your child.

Your plan will be reviewed regularly by our skilled teams, including children's nurses, therapists, play workers and social workers. They have been trained to do this by Tŷ Hafan. They will talk with you regularly, and we will not carry out any procedure unless you give your permission.

Our teams have regular training to ensure they are able to deliver the highest standard of care and all have undergone checks through the Disclosure and Barring Service.

Our services complement rather than replace the care and support that you already receive in the community and hospital. The consultant that sees your child regularly will still be the one making the decisions about your child's care. We also have a paediatric palliative care consultant and GP's who visit the hospice regularly. This consultant also supports young people moving from children to adult services.

Section 3 | **Providing Care, Being There: Our Services**

We provide a range of services that meet the needs of your child and family. This includes short break care, emergency care, and care at the very end of life. As well as providing services at the hospice, some of our services are also available at home, in community venues closer to home, in hospital or in schools:

- family and sibling support
- play and activities, including 'stay and play' hubs
- specialist therapy support which includes physiotherapy and occupational therapy as well as a play therapy, music therapy and a range of complementary therapies.

When it is needed, we also offer:

- support for young people and families moving from children to adult services
- care at the end of life
- bereavement care and support

We will allocate the most appropriate member of care services, usually someone from the family wellbeing team, to act as your main contact; this person keeps in touch with you and supports your child and family.

What is short break care?

We understand a break from caring can make a world of difference to families who live day to day with the challenges of a life-shortening condition. That's why we offer planned short break care. As we emerge from the Covid-19 pandemic, we are working to be able to provide a short break offer to all families. We will stay in touch with you so you remain informed.

Short break care gives you the chance to have a break from the care you give to your child each day. It gives you the opportunity to recharge your batteries and have an uninterrupted night's sleep and maybe spend some quality time with your partner or other children.

Short break care can involve you completely handing over the care of your child to our skilled staff. We understand this may feel daunting, so, if you prefer, we can share the care of your child, with you showing us exactly what your child needs, including when and how. We want for your child to be as comfortable as possible and to have the best care, and for you to feel confident, so we will learn from you how best to care for your child.

For your child, short break care gives them a break from home too. It gives them the chance to meet new people, to have new experiences, and to learn to trust others to care for them.

You are welcome to stay, but you may feel that you would like to remain at home. As long as you let us know, you can stay for part of the short break or all of it. We only need to know so that we can make arrangements with our chefs and housekeeping teams so you are comfortable throughout your stay.

How does it work?

Short break care is offered based on the needs of your child and your family. Short break care stays are usually for a few days at a time, but we try to tailor the timing and duration of your child's short break to meet the needs of the whole family. Our admissions team will manage your planned stays and work with the wider team to ensure we are ready to welcome you.

We will usually offer you dates for short break care in advance by email, letter, or SMS. We will always ask you to confirm your acceptance. Alternatively, you can request a preferred date, particularly for holidays or special occasions. We will always try and say yes, if we can, when you make this type of request.

We will let you know in advance any details of what is needed for your child's short break care at the hospice. We will always ask you to complete a pre-admission questionnaire – the information you share is important to help us plan for your child's stay with us.

We usually ask you to arrive and leave for your short break care at a planned time. This is so that your rooms are ready for your arrival. If you have any specific requests around when you arrive or leave, let the admissions team know and we will try and accommodate this.

Sometimes things might happen which affect your ability to care for your child, such as illness, an accident, family breakdown or a housing emergency. We may be able to help with these crises by providing your child with short break care at very short notice. Please let us know as soon as possible if a crisis like this does occur.

We will also do all that we can to accommodate families at short notice should end of life care be needed.

Sometimes the children using our services need medical or surgical treatments in hospital. If your child takes a long time to fully recover from these treatments, we may be approached by our colleagues working in hospitals to provide 'stepping stone' care before returning home. If this happens, we will carry out an assessment of your child's needs following surgery or a course of treatment in order to make sure we are able to manage their needs. We'll agree with you on the length of stay at the hospice and help you to get back home safely.

The admission process

We ask you to stay at the hospice the first time your child comes for short break care. This helps us to understand how to care for your child in the way that you do. This approach helps your child to settle, and also helps to reduce your anxiety about handing over the care of your child to others.

When your child comes to the hospice for short break care we have to make sure that we take over their care in a safe way. For this reason, we can only carry out the admission process with a person who has parental responsibility; unless other arrangements have been made before your child comes to stay with us.

Our nurses and clinical nurse specialists work with the admission team and will be in touch with you before your child's stay. They will create or review care plans and check current medications.

On the day of admission, you will be allocated a member of staff in the care services team. They will meet you, and will review your child's care plans and documentation to ensure that we have the most up to date information about the care of your child. The process also involves checking any medication that your child is prescribed and transcribing it onto a Tŷ Hafan medication administration chart so that medicines can be given safely. It is especially important that all information is accurately documented and detailed if you are not staying or if you are going away on holiday. If you are planning on travelling, abroad we will ask you details of your travel arrangements and a contact person in the UK who we can contact if we cannot get hold of you immediately.

Each time your child comes for short break care, we will ask you for up-to-date contact details, medication and treatment details and any changes in your child's care or condition that have happened since the last visit.

The information we ask for during the admission process is needed for developing your child's plan of care. Sometimes we will adapt the plans of care that professionals follow in the community or at school to include any specific needs that your child may have for that particular short break period.

If your family is staying with us, then the admission process also includes information to keep you safe such as the evacuation procedure, signing in and out of the hospice, housekeeping routines and other health and safety information.

Due to Covid-19, we have specific arrangements in place to maximise safety for everyone at the hospice. As these are subject to change, we will let you know in advance or on the day of your child's admission.

Where will we stay?

Short break care is provided at our purpose-built hospice in Sully in the Vale of Glamorgan. The hospice has recently been refurbished so will look a bit different from the last time you visited. We hope it will be welcoming for you and provide your child with a balance of stimulation and relaxation.

Your child will have their own bedroom. Each room is equipped with the most appropriate bed or cot for your child, hoists, washing facilities, wardrobe, medicine cabinet, individual air conditioning and heating, television, and a music system. All your child's feeds, medicines and equipment are stored in their rooms for the duration of the short break, apart from medication that requires refrigeration, which will be stored in the treatment room.

Some medicines are classified as controlled drugs that require secure storage in a designated cabinet. We will require the Tŷ Hafan medication administration chart to be verified and signed by a parent or carer who has parental responsibility. Where parents who have chosen to administer their child's medications during a stay, a risk assessment and consent will be completed to ensure safe medicines management. When it comes to controlled medicines, we will still need to comply with relevant legislation and guidelines under the Misuse of Drugs Act 1971.

Specialised bathing and shower facilities are situated in bathrooms opposite the children's bedrooms.

We will provide bed linen and towels but would like you to provide all the toiletries that your child uses. If your child sleeps with a particular toy or comforter, please bring that as well.

We will wash your child's clothes, unless you tell us otherwise. You may wish to label your child's clothing, but it isn't essential.

Our family accommodation is situated on the first floor, which has lift access if required. We have seven spacious en-suite bedrooms – each room is different, and some have a dedicated area for other children in the family who may be staying with you. One room is interconnecting for the use of larger families and one room has an accessible bathroom facility. All rooms can accommodate cots or 'put-up' beds. Brothers and sisters may have their own rooms if old enough.

We will provide you with bed linen and towels; all you have to bring are your toiletries. The family lounge is also situated on the first floor – it's a shared space, but it is available for you to relax, watch television, play with your other children or even cook a simple meal. The lounge has a washing machine for you to launder your family's clothes if you wish.

To maintain our high standard of cleanliness, we clean all rooms every day. We'll let you know the time we are due to clean your room. If this time is not convenient for your child and you, our housekeepers will always change the time to suit you.

Is smoking allowed?

There is a no smoking policy throughout the hospice building and grounds. This includes the use of e-cigarettes. However, special arrangements have been made for those family members over 16 years of age who wish to smoke. An outside area has been set aside for this purpose. Staff will show you this area when you come to stay at the hospice and the guidance around security procedures for ensuring doors are not left open or ajar when using this facility.

Security and visitors

We understand you may wish to have visitors during your child's stay at the hospice. Due to Covid-19, we currently have restrictions in place to reduce the total number of people on the hospice premises at any one time and minimise risks to children, families and staff. This is kept under review and may change depending on community transmission rates.

If you feel having a visitor is important, please let us know and we will talk to you about how we may be able to allow this to happen safely.

Safety of children, families and staff is extremely important, and we take security of the premises very seriously. All doors are fitted with alarm sensors and access to the building is gained through fob/access code entry. Please ensure doors are not left open at any time.

Entrance to the grounds is via a fob-activated barrier. If you leave the hospice premises during your stay, you will need to use the entry buzzer at the barrier and hospice entrance to regain access.

We are still taking extra care to manage the continued risks relating to Covid-19. If you have arranged with staff for a visitor to come to the hospice, please let them know we have put extra measures in place due to Covid-19. Please let them know that if they have any of the following symptoms, they will not be able to enter the hospice:

- A high temperature
- A new continuous cough
- A change in taste or smell.

They will also be unable to visit the hospice if a member of their household has tested positive for Covid-19 and is currently self-isolating.

When your visitor arrives, we may ask them to complete a lateral flow Covid-19 test – this will provide a quick result. If the test is negative, they will be required to sanitise their hands, check their temperature, and wear a facemask throughout their stay.

All visitors are asked to sign in for health and safety reasons for example, as a registry in the event of a fire. Information about fire and evacuation procedures is printed in each of the parents' bedrooms with a plan of the building placed on the doors to each of these rooms.

What about meals?

Meals and non-alcoholic refreshments are available for you and your immediate family members during your stay. It is not usual for us to provide meals for wider family or friends, but we can provide tea, coffee and biscuits. If you have a special occasion during your stay, please let us know and we will try and help you celebrate.

You can use the tea and coffee making facilities in the kitchen at any time during the day or night and fresh fruit, squash and other snacks are available throughout the day.

All meals are provided in the heart of our hospice where we have a dedicated space for sharing a meal. Families and staff usually sit down to eat together. If, however, you wish to eat separately please just let us know. You are welcome to take meals to the upstairs Family Lounge.

There is no set time for breakfast; you can have tea, coffee, juice, cereal and toast when you are ready. A hot cooked lunch is served at about 12:30 pm and tea is served from around 5:00 pm.

If you or your child don't fancy the meal on the menu, just let us know and we will prepare something for you.

We are able to cater for any dietary needs, if you have specific requirements, please let us know. You can also have your meals at different times, please let us know. Our catering suppliers will provide kosher meals and halal prepared meat and produce if required. You can also bring some supplies in with you if you wish. We will label and store them for you in the large kitchen fridge.

We can also provide you with a vegan or vegetarian diet and cater for you if you have specific allergies or intolerance to certain foods.

Please let us know of your dietary requirements before you come to stay at the hospice so we are prepared.

How will you care for my child?

We provide all the physical and personal care that your child needs during their short break. Our nurses will assess, plan, deliver and review a child's care through each span of duty, and the care is reviewed by the oncoming team during handover periods and at the end of a span of duty which usually takes place at 7:00 am and 7:00 pm. During their stay, your child may be reviewed by our palliative care consultant or by a GP. If you would like your child to be reviewed by a doctor during their stay, please let us know on admission or anytime during your child's stay.

Between 9:00 am and 6:00 pm, medical services for the hospice are provided by West Quay Medical Centre, Hood Road, Barry, CF62 5QN. Out of hours GP services are provided by Cardiff and Vale NHS Local Health Board.

Tŷ Hafan's paediatric palliative care consultant is usually here on two days during the week. Additionally, the care team have meetings each week to provide any extra advice that may be needed for children staying at the hospice. The Tŷ Hafan consultant works closely with the other tertiary paediatric palliative care consultants who also visit the hospice. This team provides an on-call service outside of office hours.

Your child and you will be included in all decisions made whilst you are at the hospice. If you are not staying with your child, we will keep you informed of any changes in your child's condition or treatment as quickly as possible.

If your child becomes unwell during their short break care, the hospice doctor will be able to manage most illnesses. If your child develops a serious problem then an ambulance will be called to take your child to the University Hospital of Wales, commonly called "the Heath". The children's assessment unit is referred to as 'CAU'.

Sometimes your child may need a treatment to manage their condition that is not available at the hospice and can only be provided in a hospital. If this is the case, we will work together with you and the hospital to make sure that there is a safe transfer of care.

Physical care is only a part of what we provide during short break care. Our care plans are tailored with your child in mind and allow for time to play and take part in activities or outings that enable them to thrive during their stay. Older children have the opportunity to "hang out", make friends and play up to the minute computer games. We protect our computers and televisions to ensure only material that is age appropriate is accessed.

Your child may need specific therapies such as hydrotherapy, play, sensory, music or complementary therapies to help them express their feelings, to ease pain or discomfort or just for enjoyment. We want your child to experience as much as possible, to feel comfortable and to have fun.

Sometimes your child may need to talk to someone who is not too close to them. We can provide a listening ear for fears, frustrations and to help them talk things through.

How will you care for my family?

During short break care you and your family may just want to be able to switch off. You may want to take advantage of your free time and go out each day. But you may also want to talk to someone and we can provide that listening ear for you. You may need information or sources of practical advice. This type of support can be provided by a member of our family support team.

We want you to feel relaxed during your short break stay. You are free to join us in our shared spaces, or to spend quiet time on your own.

Brothers and sisters may need to spend some quality time with you or may want to have a chat with a member of our team who works specifically with brothers and sisters – we call them our sibling support practitioner.

The hospice can appear to be a very exciting place for a child. It is also a very large building and younger brothers and sisters may get lost if not supervised. For their safety, we will always ask you to take responsibility for their care and to always keep them in sight. Brothers and sisters can join in activities taking place at the hospice and spend time playing with their sibling. We will always let you know when the activity is finished so you are clear when our responsibility is transferred back to you.

What about my faith?

Tŷ Hafan welcomes children and families from all faiths as well as families with no faith at all. You are able to observe any religious practices your family may have throughout your stay. If you wish to pray or meditate, we have a non-denominational sanctuary which can provide you with a quiet space. You can also ask for us to arrange to short services with a chosen minister or faith leader in the sanctuary.

We can provide you with guidance and information about local place of worship. We also have resources for people of all faiths in the sanctuary.

Section 3.2 Family and Sibling Support

Our family support team and sibling support service will work closely with you and the wider Tŷ Hafan team to ensure that your whole family is supported in the best way possible.

Their role will be different for each family as each family is unique. This means their support will be tailored with your needs in mind. As well as providing personalised support, they can also put you in with other families who may understand some of the challenges you face. They will also arrange social events to allow you as a family to create special memories. These teams can visit you at home, in hospital or see you when you come to stay at the hospice.

In addition to care services staff being available at the end of a telephone, the family support practitioners provide an on-call service over the weekend and after 5:00 pm each evening. If you need to speak to someone when you are staying at the hospice, ask a member of care services staff, if you are at home, just ring the hospice and the family support practitioner on-call will ring you back.

Brothers and sisters may need special help to understand the needs of their sibling with a life-shortening condition. Our sibling support team can work with siblings individually or they can join one of the sibling support groups which meet regularly to talk and have fun. You as a parent may find it hard to discuss some of these difficult things with your children, but the sibling support team can help you find the best way to talk with your children.

We also have family support workers who work specifically with mums and dads. They offer support via events, groups and when needed, individual support sessions. These can be a good way to get to know others in similar situations and have some fun at the same time.

All of this support continues into bereavement.

Play and leisure

We recognise that above all your child is a child and needs to do all the things a child does. Our team of experienced play staff are able to assess the play and leisure requirements of your child and develop a plan that both stimulates and challenges your child, but which is above all fun. Play staff can also work with hospital staff to provide this plan of care when your child is in hospital.

Your child can be assessed for outreach play at home. This service works with you and your child to create an individualised play pack which will help your child reach their full potential in play and enhance their relationship with the world around them.

A toy and leisure library is available at the hospice and is stocked with lots of specialist toys and ideas which support the work of the outreach play service. Families can also access the toy and leisure library when they are at the hospice or from home or hospital.

Our Hospital Play Specialist, who is experienced in supporting children with a range of abilities, can provide additional specialist play interventions to help your child feel less anxious about medical interventions or treatments. This support may be at the hospice, at home or in hospital.

Specialist therapy support

We can provide your child with a number of specialist therapies which are able to meet their specific needs.

Music therapy

We provide music therapy both at the hospice and in your own home. We will assess your child to see whether music therapy will meet their needs. Music may be a way that your child can communicate with the world or they may just enjoy music as fun.

Play therapy

Some children may find it is easier to express their fears and anxieties through play, our qualified play therapist can offer a course of therapy if this is assessed as appropriate and helpful. This service is also available to brothers and sisters.

Physiotherapy

Your child may need to have regular physiotherapy as part of their plan of care in the community. We can carry on this plan when your child is having short break care, including regular stretches and chest physiotherapy.

If your child develops a chest infection during short break care then we are able to provide chest physiotherapy to aid recovery.

The physiotherapist is available most week days, and can ensure staff have the skills to carry out routine physiotherapy at weekends.

Occupational therapy

We have a qualified occupational therapist as part of our team too. They can work with you and the care team to ensure that your child has the correct equipment and support

to maximise their activity. The occupational therapist can also provide community-based support and work with other professionals to ensure you and your child have the equipment and support you need at home.

Hydrotherapy

We have a purpose built hydrotherapy pool for use by children and families. Members of our team can support your child to have a hydrotherapy session to aid stretches, relieve pain and discomfort or just to have some fun. You may also wish to use the hydrotherapy pool as a family to just enjoy some time together secure in the knowledge there is help nearby if you need it. We are able to offer booked hydrotherapy pool sessions for children and families outside of a booked stay. Families will be able to use the pool but will need to ensure support is arranged through their community team and/or family members.

Complementary therapy

Your child may need a range of treatments to keep them comfortable and pain free. Massage and the use of natural treatments may work with medication to keep your child comfortable. Your child may need massage to improve circulation or to relieve aches and pains. We provide this service at the hospice and in your home or hospital.

As parents, you too can also make use of this service at the hospice, at home or in hospital.

Moving from children's services to adult services

Although your child has a condition that will shorten their life, we recognise that your child may reach their 18th birthday. At Tŷ Hafan, planning for your child to move from children's services into adult services begins when your child reaches the age of 14. This is known as transition support and includes social activities and peer support group engagement. A family support practitioner and dedicated transition support nurse will work closely with your child, you and all other agencies throughout this transition process.

We cannot provide short break care or any other form of residential support to your child and you after their 18th birthday. However, our support workers have put in place other support including our peer support group 'the squad' and parents support groups, such as the mum and dad groups. They continue to be available long after the discharge from the care service. In addition, you can continue to be supported by the team until you are settled into adult services.

End of life care

When the time comes, you need to know what we can offer your child and you at the end of their life. There are many decisions you and your child will have to make but our expert staff will be there to support your whole family through this difficult time.

You may want to spend your child's final days, weeks or months at home, in hospital or at the hospice. Wherever you decide, we will work with your child, you and all professionals involved with your child's care to try and ensure the care you want and need is available in the right place and at the right time.

If your child makes some small improvements, you may wish to reconsider your plans, and think about returning home. We will work with you and all the professionals to ensure that a plan of care is devised to reflect this change of condition and the probability that they may need increased support at home.

How could you support us at home during this time?

If you wish to remain at home, or in hospital for your child's final days, weeks or months, a family support practitioner will provide your child, you and your family with the information and emotional support you all may need. They will work with our wider team, including our clinical nurse specialists, and our play and therapies team to provide you with tailored support.

Our complementary therapy service will be able to offer your child soothing and relaxing massage, to ease discomfort and pain. This service is also available for you to help relieve some of the fearfulness and anxiety of caring for your child at the end of their life.

When your child dies we will be there for you, and can offer support including help with registering the death and making arrangements with the funeral directors. We can also assist you with the funeral arrangements, and in some cases liaise with others who may be involved after death including the coroner or the police.

How could you support us at the hospice?

If you choose to come to the hospice for the final days or weeks of your child's life then you will be able to use all the same facilities as you would for any other stay. We realise that your family may need to be close to your child and that you may not want to socialise with other families - we will set up a bedroom next to your child's room so that you can stay close, but also have some time alone. Our team will support you in a way that is right for you.

Our hospice nurses and doctors will make sure that your child is comfortable.

You may wish to contact your faith group, particularly a minister, Imam or other religious leader. They are welcome to visit at any time. There may be some situations where we need to put in place some extra steps – but we will not place barriers in the way of your accessing the spiritual care and support you need. If you do not have someone you know, then we can contact a local religious leader for you. Our staff understand some of the important religious practices of many of the world faiths, but we will work with you to make sure we are carrying out your exact wishes at this time.

At this time we will make it as easy as possible for your family and friends to visit and say goodbye.

Brothers and sisters may need extra help and support in understanding what is happening. Our teams will gently explain and work with them to help you all make choices about being present during the final hours or days of their brother or sister's life.

When your child dies, we will provide you with the support you need, including explaining the processes for registering the death and helping you to make arrangements with the funeral directors you may wish to use. Your child can be cared for at the hospice following death and you are welcome to stay for a few hours or days, depending on what you need.

Bereavement support

Our specialist teams will be there for you through this very difficult and unfamiliar time. We will support through the very early days of your grief, through the funeral and then as you begin to live life without your child.

We provide this support to you and your family for as long as you need it. We can visit you at home or you may wish to join one of our bereavement support groups. We can also arrange professional counselling support if needed.

Brothers and sisters may need some special help. They may begin to experience problems in school or show changes in behaviour. If you would like us to, we are able to work with schools to provide the support that they need at this time. Sometimes children need more specialist support to help them understand their feelings, if needed we can offer a course of Play Therapy.

As part of our bereavement support, we also offer you and your family opportunities to remember your child throughout the year. A service of remembrance is held in the summer and at Christmas.

A book of memories is available for you to include pictures and memories of your child if you wish. A pebble will be engraved with the name of your child and placed in the garden of remembrance, or, if you prefer you can take this pebble home with you.

The children we have supported are an inspiration to us and all we do. We have a dedicated memorial in our gardens called 'Forever in our skies'. If you would like to know more about this lasting tribute to the extraordinary children we meet, please ask a member of our team.

This booklet outlines the services that Tŷ Hafan is able to provide for your child and your family. We can only provide the best care if we work together with you to provide family centred care and support, including letting you know what you can expect from us, how we can resolve issues if they arise and learn together if things need to be changed or improved.

We will always treat you with courtesy and respect, and we know you will always try and do this too. While we understand that coping with your caring responsibilities may sometimes cause strain and exhaustion, it is important that our staff feel safe at all times. If a member of our team feels behaviour is unreasonable, they will try and explain this to you. When necessary they may call for help or ask you to leave. Unreasonable behaviour may include swearing, physical or verbal abuse and drunken behaviour.

Please take time to read through the Family Agreement which you will have received along with this guide.

Making suggestions, raising concerns and complaints

Tŷ Hafan is regulated by Healthcare Inspectorate Wales (HIW), which undertakes regular inspections to monitor the standard of care being provided to your child and your family. Tŷ Hafan's last inspection took place in October 2021. You can obtain the latest inspection reports on our website www.tyhafan.org or on request from HIW.

Parents, carers, children and young people can contact HIW at any time if you feel that we are not meeting the required standards for health care provision. Their details are available through their website as follows:

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

Tŷ Hafan aims to ensure that the care and support it provides is of the highest possible standard. As a learning organisation, we want to understand your experiences, especially about things you feel we could do better or differently. Please let us know your suggestions on your experience of our service.

We always want your comments on the service you receive, and we may ask you, from time to time, to complete surveys or questionnaires to monitor how well we are doing. We will provide you with the results of the feedback we get.

If you feel concerned that Tŷ Hafan has not met your expectations and you wish to raise a concern or make a complaint about any of Tŷ Hafan's services, a policy and procedure is in place to guide you through the process.

Wherever possible, we encourage families to talk to us about any concerns they may have so we are able to make a difference as quickly as possible.

The procedure for making suggestions, raising concerns and complaints is set out in Tŷ Hafan's complaints policy which is available on our website <https://www.tyhafan.org/contact-us>. You can also ask any member of staff for a copy of the complaints policy.

If you wish to make complaints anonymously, Tŷ Hafan will undertake the same process of investigation, but it does mean that the individual concerned and the organisation are unable to resolve the issues 'face-to-face'.

We want our care to be the best it can, but if you find that you have a question, concern or complaint about the care you receive then we want to discuss this with you as soon as possible. You can ring us, write to us or access the website to let us know your concerns and we will investigate. We will let you know the outcome of this and discuss with you a way forward.

You can contact us at any time in any of the following ways:

Tŷ Hafan
Hayes Road
Sully
Vale of Glamorgan
CF64 5XX
Website: <https://www.tyhafan.org>
Telephone: 029 2053 2200

Thank you for reading Tŷ Hafan's Parent and Family Guide. If you or someone close to you would like this information in a different format or language, please let us know. We realise that a booklet such as this cannot answer all your questions and that there may be something that has not been included that you are concerned about. Please do not hesitate to contact us, we want you to feel safe and secure with any of the care services that we offer to you, no question big or small is too much for us to answer.