

Keech Hospice Care's children's services



Welcome to Keech Hospice Care

Our children's service supports families from across Bedfordshire, Hertfordshire and Milton Keynes who have a child or young person diagnosed with a life-limiting condition.

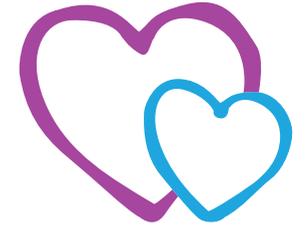
We are pleased you have chosen our children's hospice service to support your child and look forward to meeting you and your family.

Our children's service consists of an in-patient unit, community nursing team, day support and supportive care team, all of whom will support your child and family, both at times of crisis and when you need our specialist care from day to day.

You can relax, safe in the knowledge that your child is receiving high-quality support from our team of nurses, doctors, therapists and social workers.

Experience tells us that – even after looking around the hospice or being told about us by other people – patients, families and carers still have many questions. This booklet should answer the questions we get asked the most.

How we can support you



We offer a variety of services to children and families, dependent on individual family needs.

Community support

The children's community team provides care to children with life-limiting conditions in a variety of settings: the family home, at school or in hospital. The team is made up of experienced children's nurses and palliative care support workers.

The care offered by the community team varies according to each individual family's needs. This support may include providing practical advice and emotional support for the whole family, symptom management and care at the end of life. The team will also be involved in liaising with other agencies involved in the child's care, and giving advice and information relating to the child's condition, their care or social welfare.

Should a family wish for their child to die at home, the community team will help facilitate this, offering both practical and emotional support.



In-patient unit

The children's in-patient unit is a purpose-built facility that opened in 2000. There are five children's beds and accommodation is available for families to stay. The building is wheelchair accessible and disability friendly.

The in-patient unit adapts to the changing needs of the children and families that access the service. The same service is offered to all children and families.

The unit is staffed by experienced children's nurses and a team of skilled health care assistants. All staff receive training, some of which is very specialised to meet the children's care needs. Many areas of training are updated annually.

Our medical team is in the hospice providing care 9am-5pm, seven days a week, and is on call outside these times to support the nursing team.

Facilities include an aquatic therapy pool (for more details, see Supportive care services, page 12), multisensory room, teenage room, large play area and a sensory garden (for more details, see Your questions answered, page 15).

The specialist palliative care provided by the unit includes helping to control a child's pain and symptoms, access to complementary therapies, and providing emotional support. If a child or family wishes, they can also choose the hospice as the preferred place of death for their child. If this is the case, our staff will do everything they can to ensure your child's final days are as peaceful and pain free as possible. They will also provide vital support for you during this very difficult time.

On occasion, short breaks in the in-patient unit can be arranged to support families - for example, if a carer becomes unwell or during home renovations that may affect the child's health. However, short breaks cannot be guaranteed and all admissions will be prioritised according to the needs of individual children and their families.

Please be aware that all staff are trained in basic life support and use of the defibrillator. In the case of an emergency, 999 will be called.

Bed nights are allocated in the following order of priority.

Priority 1:
end-of-life care



Priority 2:
symptom management



Priority 3:
crisis intervention or
transitional stay from
hospital



Priority 4:
respite or short breaks

Priority 1 and **Priority 2** beds can be booked at any time. The hospice always tries to fulfil these requests as quickly as possible, dependent upon bed availability and staffing levels/skill mix of staff.

Priority 3 beds will be fulfilled as quickly as possible to ensure safe care of the child but are also dependent upon bed availability at the time.

Priority 4 beds are bookable on request, subject to the patient having a social care package in place and this being in line with the request. These stays can be subject to either cancellation at short notice or a reduction in length of stay depending on other requests for bed nights at the time.

Day support services

Day support provides specialist palliative care nursing, focused play and educational activities, symptom management, and memory work. This support can take place at the hospice or in the community.

The day support team consists of:

- a specialist paediatric nurse
- play specialist
- health care assistant (HCA)
- a range of volunteers.



24-hr
children's
advice line

Keech Hospice Care offers telephone support **24 hours a day, seven days a week**, through our **free** advice line:

0800 035 6497

Your call will be answered by a member of staff from children's services and specialist nurse advice is available when needed.

Day support is offered to children and families for a specific period of time to achieve an agreed goal and usually lasts six weeks. However, this can be extended if necessary.

Day support at the hospice is primarily run **Monday to Friday, 10am-3pm**. However, this can be flexible, according to the needs of the child and family. Day support sessions in the community last for one to two hours.

For those children attending the hospice for day support sessions, there is a purpose-built care area which includes a multisensory room, play area, teenage room, educational IT equipment and changing facilities. (For more details on these facilities, see Your questions answered, page 15.) A parent or carer may need to attend some sessions. This will be discussed with you when planning your child's sessions.

Parents need to be present for day support sessions carried out in the home by one of our play specialists.

Parents or carers who have booked a complementary therapy session at the hospice can use the day support facilities, where their child will be cared for while they are having their therapy session. These sessions must be booked in advance, including arranging for care of the child.

Day support also offers:

- weekly Tots 'n' Toys group for children under five years old
- Parents Supporting Parents – a parent-led support group
- specialist palliative care clinic appointments
- a range of events and activities.

Referrals to day support

Referrals can be made by both internal and external health and social care professionals. Parents or carers can contact their Keech community nurse or community palliative care support worker to request a referral.

Attendance

Attendance is flexible, according to need. We can provide transport if there are no other means for the family to attend day support: where possible, a volunteer driver, accompanied by a member of staff, will collect and return children to their home or school.

Supportive care services

Working alongside our specialist nursing care, we offer families supportive care services which can help physically, psychologically and emotionally. These include music therapy, art therapy, pre- and post-bereavement support, and a range of complementary therapies. All these services are free of charge and we have dedicated rooms at the hospice where therapists are able to work in a quiet, relaxed environment.

If you are considering a supportive care service, either for your child, yourself or a relative, please ask to speak to a member of the care team who can refer you to the supportive care team for assessment.

Complementary therapies, art therapy, music therapy and one-to-one talking support are usually offered for up to six sessions then reviewed; this ensures we offer you the most appropriate type of therapy and monitor its effect. Bereavement support continues for as long as there is an appropriate need.



Music therapy

Music therapy at Keech Hospice Care can offer psychological and emotional support for patients, their families and carers. With the support of a music therapist, you can use music to help express your feelings and emotions in a safe and secure place.

Music therapy can offer the opportunity to:

- communicate issues that may be difficult or confusing
- communicate thoughts and feelings, without necessarily the need for words
- think about loss
- be supported emotionally
- be creative and expressive
- make choices or take control
- share and interact
- encourage physical movement.

When children take part in music therapy, they can do so in our fully-equipped music room which has guitars, drum kits, keyboards and more.

You don't need any musical experience to participate in a music therapy session – the instruments can all be played intuitively. The music therapist does not teach you how to play the instruments; the focus is on improvisation.

Sessions can also include:

- writing songs
- making music CDs
- singing
- family work
- memory making onto CD or DVD
- listening to music.

The music therapist holds postgraduate qualifications in music therapy and is registered with the Health Professional Council.

Art therapy

Art therapy is the use of art materials to express thoughts, feelings and experiences in a safe environment. Art therapy is particularly appropriate when working with children and young people as being creative and having fun is a normal part of growing up.

Art therapy can support children and young people in a variety of ways. These include:

- being creative
- providing a different way of communicating
- communicating issues that may feel difficult or confusing
- expressing feelings
- exploring changes
- thinking about loss
- helping with pain.

The art therapist will provide a safe and private space for making art and talking. There's no need for you or your child to be good at art to find it helpful.

The art therapists at Keech Hospice Care hold postgraduate qualifications in art therapy, are accredited by the British Art Therapy Association and registered with the Health Professional Council.



Complementary therapies

The children's service benefits from a dedicated complementary therapist who offers reflexology and reiki. These have been chosen as particularly appropriate for children with complex health needs and are offered at the hospice or in the child's home, depending on individual need.

Both of these therapies can:

- help reduce the symptoms of illness, such as pain, nausea, breathlessness and fatigue
- improve sleep patterns
- help reduce the side effects of treatments
- reduce anxiety, low mood and distress
- reduce muscle tension.



Family members directly involved in care can access complementary therapies such as aromatherapy, reflexology, reiki, massage, Indian head massage and the relaxation method M technique. These are provided by a team of registered therapists, most of whom are volunteers, managed by the complementary therapy co-ordinator. For more information, ask for our leaflet *Complementary therapy for children and their carers*.

Bereavement support

In children's services, pre- and post-bereavement support are offered to all members of the family affected by living with a child who has a life-limiting condition and/or by the death of a child. This support is arranged to meet the family's individual needs and requirements, and will continue for as long as there is an appropriate need.

Post-bereavement, our care team, family support worker and social worker can help the family deal with the practical matters that follow the death of a child, such as registering the death and making funeral arrangements. They will also offer emotional care and support to the family during these difficult days.

Families can receive support through a range of bereavement-focused services and events.

Sibling support, where we focus on the needs of brothers and sisters of the children referred to the hospice. Inevitably, healthy brothers and sisters can feel left out as their parents focus on the life-limited child. They may experience feelings of guilt, anxiety or neglect and it is important that they have access to specialised support to help them address these feelings.

A monthly parent support group for bereaved families who have used the children's service. This support group gives family members the opportunity to discuss their feelings with others in similar circumstances, manage their grief together and recognise that they are not alone.

One-to-one support for those who prefer to talk to one person. Our family support worker and bereavement visitors (volunteers trained to support people affected by death) can see people individually, in a mutually agreed place - including at home - and at a convenient time.

The Meadow Suite, a special bedroom at Keech Hospice Care where children can stay after their death. The suite has its own access where family can spend time privately with their child after he or she has died.

Remembrance events, held twice a year. The first is **Daffodil Sunday**, which usually takes place in the spring, when families whose child has died can meet to remember their child with others in similar circumstances, alongside having the chance to talk to staff.

The second event is **Light up a Life**, an opportunity for families to attend a service in December and dedicate a light in memory of their child.

Social work

When a child has a life-limiting illness, many aspects of family life are affected. The hospice social work service is part of the multidisciplinary team providing psychological, emotional, social and practical support to children and their families, pre- and post-bereavement.

Social work support can be offered directly to children and their families on an individual basis, and can involve information sharing and advice on issues such as education, housing, finances, charity applications, transition, equipment, holidays, support with funeral arrangements and access to statutory services.

The social worker liaises directly with a range of professionals in both the statutory and voluntary sectors, and takes the lead in all aspects of safeguarding children within the hospice services.

Aquatic therapy (hydrotherapy)

Aquatic therapy is the term more commonly used nowadays than hydrotherapy to describe the use of water for therapeutic purposes. An aquatic therapy/hydrotherapy pool is very different to a general public swimming pool.

Our 16.5 metre pool is carefully designed to cater for the needs of people of all ages and disabilities. The water is kept at a constant temperature of **34°C**, providing a lovely warm environment (most public pools have a temperature of **29°C**). There is special sensory lighting, an underwater music system and a number of water fountains to make the experience all the more enjoyable.

The facility comes complete with hoists, ramps and disabled changing rooms to ensure access for all.



Your questions answered

Who will be looking after my child?

Keech Hospice Care's children's services are staffed by qualified children's nurses who are experienced in palliative care and specially trained health care assistants. They are supported by specialist doctors, a social worker, and a supportive care team including music, art and complementary therapists, some of whom are volunteers. You will also come across other volunteers who give their time and expertise in a range of areas.

Can we arrange a visit to the hospice beforehand?

This can be arranged by a community nurse and a member of staff will take you round the unit so you can view our facilities and have any questions answered. We also offer 'stay and play' sessions to familiarise your child with the environment. These sessions, usually around two hours, are also arranged via the community team and a member of staff will stay with you throughout your visit.

What can we expect when we first arrive?

Shortly after you and your child arrive, one of our doctors and a nurse will meet with you to discuss your needs. They will assess your child and take their medical history. Our social worker may visit you if you require any practical support and advice.

Following this, we will put together a care plan of how we can support your child. We will check and update this regularly to take account of changes in your child's circumstances.

Throughout your child's stay, we will give you clear explanations of your child's condition and any treatments, investigations or procedures we propose. We encourage children and parents to share in the decision making about treatment and care options.



What do we need to bring with us for a stay?

When coming to the in-patient unit, you should imagine that your child is going for a short stay in a hotel that provides food, bed linen and towels. You will need to bring your child's personal toiletries and clothes (likewise for other family members, if you are staying in the family accommodation). Please feel free to bring pictures or other personal items to put on your child's bedside cabinet or pin board to make them feel at home.

You will need to bring any special equipment, specialist feeds, medication and supplies you use in your child's care. If you're unsure what to bring, just give us a call to check.

A few days before admission, we will ask you to send us details of your child's medication. It is essential that this information is provided in advance so that we can ensure safe management of your child's care. Without this information, your stay may have to be cancelled.

Can I stay overnight with my child?

The hospice is here to support the whole family, both emotionally and practically, and we encourage parents to stay at the hospice. This is essential for a child's first stay. If a child requires a step-down stay from hospital, a parent may also need to stay so they can be supported with changes in their child's care needs. We have private family accommodation available for parents and siblings. There are sofa beds in the children's bedrooms if you wish to be closer at night.

Can our family and friends come too?

We have a philosophy of involving family and friends as much as we can and as much as you or your child want. As previously mentioned, there is family accommodation available that your family is welcome to use if they would like to stay overnight.

Visitors are welcome. On arrival, they should report to the children's reception desk and sign in to the building (this is important in case we need to evacuate).

Out of hours, the nurse in charge of the shift should be made aware of planned visitors as the front door is locked and reception is unstaffed. Visitors must ring the doorbell and nursing staff will let them in. Staff may not be able to answer the door straightaway if they are attending to a child so we ask visitors to be patient. We also ask that visitors are sensitive to the needs of all patients and families who are staying at the hospice.



What facilities are there for play and recreation?

There is ample provision at the hospice for play and recreation as well as specialist facilities for therapies and learning. The facilities include:

- a multisensory room with colourful lights and tactile toys to encourage a child's movement and senses
- a sensory garden designed for children of all abilities, including those who use a wheelchair
- a teenage area with widescreen television, music system, games console and computer
- an aquatic therapy (hydrotherapy) pool - often one of the first things our children and their families want to use!

How children and their families use these hospice facilities depends on their needs and wishes. Staff support may be required for safe access to some areas.

What about meals and refreshments?

Keetch Hospice Care provides an extensive menu from our in-house restaurant, Valerie's. It caters for patients' varying cultural and dietary needs. Family members who are staying overnight in the hospice with the patient are welcome to order from the menu free of charge. Food can either be ordered and delivered to the in-patient unit or you can visit Valerie's. Additional family members and visitors are welcome to purchase meals from Valerie's; there is also a vending machine with confectionery items and soft drinks in the restaurant. Tea and coffee is available for patients, family members and visitors from the kitchenette on the unit, free of charge; however, there is a money box if visitors wish to donate. Basic items - such as tea, coffee, milk, bread and so on - are also provided in the family accommodation.

Can we bring our pets to visit?

You may bring pets to the hospice, within reason. Please ring us beforehand as we may have other children, families and staff members who have allergies or are frightened of animals. Visiting pets are easier for us to manage than ones that stay overnight and it is usually less distressing for the animal, too. If you wish a pet to stay overnight, please discuss this with staff members in advance.

We allow working animals like guide dogs, PAT dogs, hearing dogs for the deaf and dogs for the disabled in all departments.

I smoke or members of my family smoke. Is this a problem?

We do not allow smoking within the hospice building but you or your visitors can use our designated outside smoking areas. Please ask a member of staff where these are.

Can we make and receive telephone calls while at the hospice?

You can use mobile phones at the hospice, but we ask everyone to be considerate when using their phone and take care not to disturb other families.

Do we have to pay for anything?

Our service is free to patients. You will need to bring a small amount of money with you if you wish to buy items from the hospice shop (located in the main reception area) and our vending machine.

Is there somewhere we can go for quiet reflection or to practise our faith?

Yes, there is a lounge in the family accommodation area and a quiet room next to reception in the adult hospice for patients, families and friends to use if they need some time and space of their own. Your own clergy are welcome to visit at any time or you can ask to see one of the local ministers/leaders who visit the hospice regularly. Families can, of course, ask for complete privacy in the child's bedroom, if necessary.

What about security?

Security is a very important issue - not only the security and safety of children, visitors and staff but of the physical building and contents, too. Regrettably, criminals do target the hospice.

You and your visitors can help by being vigilant.

- Please ensure you take care of your possessions, and those of your child, by using the lockable cupboard in your child's room for any valuable items such as mobile phones, money and music players. The hospice cannot take responsibility for your belongings or money.
- Please ensure you close any external doors or windows you have opened after use.
- All hospice staff wear identity badges. Care staff working in the in-patient unit wear uniforms.
- The hospice depends on a team of volunteers who do a wide variety of tasks around the buildings and gardens. They all wear identity badges, too.
- In the unlikely event you see anyone acting suspiciously, or who isn't wearing an identity badge, please tell a member of staff.

How do we keep in touch?

Every child is allocated a community nurse who is your first port of call if you have any questions. We also produce a quarterly newsletter, usually sent out by email, which gives details of all up-and-coming events and activities as well as news about our services.

What if there's a fire?

When the fire alarm sounds, listen to whether the siren is continuous or intermittent.

Continuous This is the evacuation alarm: all visitors must leave the building immediately by the nearest exit and gather at the Assembly Point. This is the visitors' car park at the front of the adult hospice. Please close all doors behind you.

Intermittent This is the stand-by alarm. It means you should stay in the building for the time being but be prepared to evacuate if necessary. If it changes from intermittent to continuous, this means your area now needs to evacuate. Follow the instructions under 'Continuous'.

We do not evacuate the children immediately since this can be distressing. The hospice has high-quality fire doors that slow the progress of a fire through the building to such an extent that the fire brigade will be present well before a serious situation can develop. Should evacuation become necessary, nursing staff will be with your child throughout.

If you discover a fire, please isolate it by closing doors around the area (if possible) then tell a member of staff. Do not try to tackle the fire yourself. If there is likely to be any delay in approaching a member of staff, please sound the alarm.

What if I, my child or one of our visitors has an accident?

If you, your child or any of your visitors suffer an injury or have an accident while at the hospice, it is important that you tell a member of staff, however slight the accident. The charity is legally required to record all accidents and injuries on an accident form.

What if we want to register a comment, compliment or complaint?

We take great pride in the quality of service we offer. If you have any comments or suggestions about our service, we would welcome your views and have placed a suggestion box in the unit. If you wish to make a complaint about any aspect of your child's care or treatment, you can do this verbally to any member of staff or in writing to our Chief Executive Officer.

We record and act upon every comment or complaint according to our complaints policy, dealing with it quickly and confidentially while keeping you informed throughout. For more information, please ask a member of staff for our *Comments, compliments and complaints* leaflet.

What do you do with my child's information?

The charity is bound by the General Data Protection Regulation 2016 and takes its responsibilities very seriously.

We promise to:

- take great care of the information you share with us about your child and uphold the highest levels of confidentiality
- only share your child's health care information with other professionals and health care workers when they need this information to provide their care. We may also use your child's records in research and audit projects. You will be asked to sign a 'consent to share' form which enables us to share information with other professionals. This requires updating annually.
- always seek your permission, or that of your child, first if we intend to use your information in any other way that you might not expect.

If you would like to know more about how we use your child's data, including details of how you can access/read your child's medical notes, please ask a member of staff for a copy of our *How we use your information* leaflet.

Who regulates your service?

The Care Quality Commission is responsible for regulating and inspecting voluntary and private health care organisations.

For a copy of our most recent inspection report, please contact our Chief Executive Officer at the hospice or visit the Commission's website at www.cqc.org.uk.

Alternatively contact:

CQC National Customer Service Centre
Citygate, Gallowgate,
Newcastle upon Tyne, NE1 4PA
Tel: 0300 061 6161

Can we find out what others have said about your service?

Every year, we survey our families to find out what they think of our service and their levels of satisfaction. We collect the results of these surveys into a summary and make it available to the public. To see the results of our latest survey, please visit our website, ask a member of staff or call 01582 497871.

If you could find the time to complete any surveys we send you, this will help us to improve and develop our service.

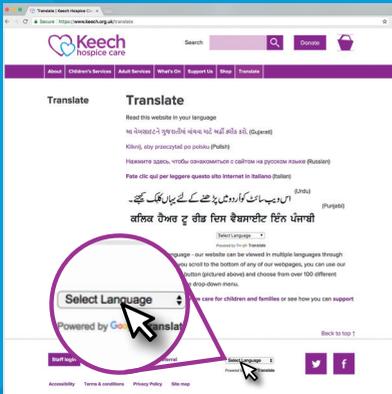
How do we comment on this guide?

If you have any comments or suggestions on what could improve this guide for others, please contact the Head of Marketing and Communications at the hospice. You may find our *Statement of Purpose* useful. To receive a copy, please ask a member of staff, download it from our website or contact us on 01582 497871 and we'll send you a copy.

If you would like this information in other languages, please visit www.keech.org.uk/translate.

Where we provide care

- Children's service
- Adult and children's service



As a charity, around **70%** of our funding for our care services comes from our local community and supporters. This means we need to raise around **£6 million** every year to provide our specialist care for children and adults with life-limiting and terminal illnesses, and their families.

To help us continue making the difference when it matters the most for patients and their families, please donate at www.keech.org.uk/donate.